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MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT OF 1987

HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH

OF THE

COMMITTEE ON FINANCE

UNITED STATES SENATE

ONE HUNDREDTH CONGRESS

SECOND SESSION

ON

S. 1673

MARCH 22, 1988

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MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT OF 1987

TUESDAY, MARCH 22, 1988

U.S. SENATE,
COMMITTEE ON FINANCE,
SUBCOMMITTEE ON HEALTH,
Washington, DC.

The subcommittee met at 9:38 a.m. in room SD-215 of the Dirksen Senate Office Building, the Honorable George J. Mitchell, chairman of the subcommittee, presiding.

Present: Senators Mitchell, Packwood, Chafee, Durenberger and Heinz.

[The press release announcing the hearing follows:]

FINANCE SUBCOMMITTEE ON HEALTH TO HOLD HEARING ON MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT

WASHINGTON, DC.—Senator George Mitchell (D., Maine), Chairman of the Senate Finance Subcommittee on Health, announced Friday that the Subcommittee will hold a hearing on S. 1673, the Medicaid Home and Community Quality Services Act of 1987.

The hearing is scheduled for *Tuesday, March 22, 1988 at 9:30 a.m.* in Room SD-215 of the Dirksen Senate Office Building.

Mitchell said, "This legislation, sponsored by Senator John Chafee, (R., Rhode Island), is intended to encourage states to provide expanded home and community-based services for the developmentally disabled, a concept which has been implemented in a number of states including Maine and Rhode Island."

"The bill is the product of several years of discussion with a wide variety of organizations. The hearing will provide an opportunity for interested groups to express their comments and concerns about the bill and the impact it may have on the lives of the developmentally disabled and their families," Mitchell said.

OPENING STATEMENT OF HON. GEORGE J. MITCHELL, A U.S. SENATOR FROM THE STATE OF MAINE, CHAIRMAN OF THE SUBCOMMITTEE

Senator MITCHELL. Good morning, ladies and gentlemen.

We are here today to examine the Home and Community Quality Services Act, introduced by Senator Chafee. The legislation is the product of a number of years of diligent work and commitment by Senator Chafee and his staff, and others who are concerned about the quality of life of the developmentally disabled.

While this Committee has not held a hearing on this version of the legislation introduced in the 100th Congress, a number of hearings have been held on previous versions of the bill and on the general issues of Medicaid financing of services for developmentally disabled persons.

In September 1986, this Subcommittee held a hearing on the issue and focused specifically on how to balance Medicaid funding between institutional settings and home and community-based facilities for the developmentally disabled.

In recent years, there has been a significant change in the treatment of the developmentally disabled. Thousands of persons who had been in large public institutions have been placed in community-based settings. Between 1977 and 1986, the total population of state institutions of 16 beds or more decreased by one-third. This movement toward community-based treatment facilities has been a positive experience for many citizens, but this movement away from large institutions has also brought new challenges and problems.

Of the $5.2 billion in federal and state funds used to care for the developmentally disabled in fiscal year 1986, 75 percent was allocated for residential services in state institutions of 16 beds or more. The primary support for community-based services continues to be state dollars.

This bill is intended to restructure the Medicaid program to better meet the needs of the developmentally disabled, while promoting greater independence and productivity for these citizens. The legislation we will discuss today would gradually shift federal Medicaid dollars away from large institutions to make more federal funding available to community-based facilities.

Many states, including Maine and Rhode Island, have developed a system of home and community-based care for the developmentally disabled which has been successful and widely supported by the disabled and their families. Passage of this legislation will support these efforts and encourage other states to develop similar models.

I am a co-sponsor of this legislation. I support the bill because I am aware of the widespread support of deinstitutionalization for the developmentally disabled in my own State of Maine and across the country. I am also well aware of the strong opposition to this legislation by some persons and organizations who are equally concerned about the quality of life of the developmentally disabled.

The legislation is not perfect. It can, as with all legislation, be improved. I look forward to hearing from all of the witnesses today, and am genuinely interested in the views which will be presented by those in favor of the bill and those opposed to it.

I will continue to work with Senator Chafee and other Members of the Committee to refine this legislation so that we can pass a bill that will best provide options for the nation's developmentally disabled citizens and enhance the quality of their lives, which I believe is the common objective shared by every single person in this room.

I now call on Senator Chafee for his opening remarks.

OPENING STATEMENT OF HON. JOHN H. CHAFEE, A U.S. SENATOR FROM THE STATE OF RHODE ISLAND

Senator CHAFEE. Thank you very much, Mr. Chairman.

I want to express my appreciation to you for scheduling this important hearing. Today we will be hearing and considering the views of a broad spectrum of organizations on this legislation which I introduced in September of last year. The name of the bill, as you pointed out, is Medicaid Home and Community Quality Services Act of 1987. This bill will revolutionize the services and support provided to those who are mentally or physically disabled.

To date, 35 Members of the Senate have co-sponsored this legislation. Eight are Members of this Finance Committee. And we are proud that you, Mr. Chairman, as you mentioned, are one of those co-sponsors.

There are people in the audience today from all over the country, people who have strong feelings about this bill, both in support and in opposition. I want to thank each of the witnesses who will be appearing before us today for taking the time to join us and to show your interest and to provide us with your thoughts and views. Your presence points out the critical need for Congress to develop a Medicaid program that will truly meet the needs of individuals with disabilities and their families.

I have reviewed the testimony to be presented today. It expresses many legitimate concerns, suggestions for improvements and views on basic philosophy. Today will certainly be an opportunity for Members of this Committee to listen to a healthy exchange of views.

One common theme through all the testimony, both in favor and opposed, is concern about the lack of community-based services for those with physical and mental impairments. The disagreement arises when we begin to discuss how to expand and develop community-based services in order to achieve a system that represents a variety of choices for individuals needing services. I think every witness will say we should have a variety of choices. The problem is, how do we get that variety?

As many of you know, this debate has been going on since 1983 when I introduced the first legislation on this matter. The two previous bills, candidly, were deinstitutionalization bills. They would have eliminated all or a substantial part of federal funding for services provided in large institutional settings. We had hearings on those measures in the Finance Committee, and I talked to countless individuals across the country and organizations as well who were opposed to those bills, and we had hearings in different sections of the country.

Those hearings convinced me that those bills went too far. Those opposed to the deinstitutionalization aspects of the legislation have won a victory. We have gone from zero funding in the original legislation to 100 percent funding for institutions. Now, the freeze in the current version of the bill is not a deinstitutionalization provision. Instead, it is a provision designed to ensure that community-based services will be developed and that those living in institutional settings are appropriately placed.

I hope the Committee will act on the bill this year. This is compromise legislation. It is the product of five years of discussions and a consensus of all the major groups representing those with developmental disability. We have moved a long way to accommodate the concerns of some of those who have relatives or children in institutions of over 15 beds. Now it is time for all of us to move to accommodate the concerns and needs of hundreds of thousands of individuals and families who desperately need assistance and who do want a choice in how that assistance is provided.

Mr. Chairman, I want to include in the record, cost estimates that I have obtained over the telephone from Mr. Donald Muse. Of course, all of us know Mr. Muse from the Congressional Budget Office. I would like just briefly to mention them, Mr. Chairman.

In the first year, the bill costs $30 million. In the second year, it saves $430 million. The third year, it saves $105 million. The fourth year, it is zero. The fifth year, it costs $100 million. The sixth year, it costs $200 million. And year seven and beyond cost $300 million in addition. All of these are on a base line; namely, what we are spending now.

I look forward to an interesting and helpful hearing which I hope will lead us to action in the near future, and again I want to thank you, Mr. Chairman.

Senator MITCHELL. Thank you, Senator Chafee.

We are pleased to have present the former Chairman of the full Finance Committee, the distinguished Senator from Oregon, Senator Packwood.

Senator PACKWOOD. Mr. Chairman, thank you.

I have no opening statement. I think I have seldom seem a subject—and I understand the divisions on this—I have seldom seen a subject where I find everyone, no matter which side they are on, so well motivated and with a desire to achieve the same end, coming at it from diametrically different viewpoints. I hope there is a way we can harmonize all of the positions on this side because there is no question but what everyone has the public interest at heart.

Thank you, Mr. Chairman.

Senator MITCHELL. Thank you, Senator Packwood.

The first scheduled witness is Senator Weicker. I understand that Senator Weicker has been detained at a prior hearing that he is attending.

The next scheduled witness is Representative Steve Bartlett of Texas. Is Representative Bartlett here?

[No response.]

Senator MITCHELL. Then we will proceed to the first panel of three persons. As I call your names, please come up and take a seat at the witness table: Mr. K. Charles Lakin, Director of Research, Minnesota University Affiliated Program on Developmental Disabilities/Center for Residential and Community Services; Ms. Valerie Bradley, President, Human Services Research Institute, Cambridge, Massachusetts; and Mr. Ronald Welch, President of the National Association of State Mental Retardation Program Directors, and Associate Commissioner of the Maine Department of Mental Health and Mental Retardation.

Good morning, Ms. Bradley and gentlemen. For your benefit and for the benefit of all subsequent witnesses, I would like to state at the outset the Committee's rules and procedures regarding testimony. All written statements will be included in the record in full for review by all Members of the Committee. Each witness is asked to limit his or her oral remarks to five minutes. We have a very long list of witnesses today and we want to give everybody the opportunity to be heard and have an exchange with the senators who are present.

So we are going to strictly enforce the five-minute rule. And to help you with that, immediately before me you see a panel of lights. They are the same as traffic lights. As long as the light is green, keep going. When it gets to be orange, think about slowing down. And when it is red, stop.

With that, we will now proceed to hear from the witnesses, and we will begin with you, Mr. Lakin. Welcome. We look forward to hearing from you.

STATEMENT OF K. CHARLIE LAKIN, DIRECTOR OF RESEARCH, MINNESOTA UNIVERSITY AFFILIATED PROGRAM ON DEVELOPMENTAL DISABILITIES/CENTER FOR RESIDENTIAL AND COMMUNITY SERVICES, MINNEAPOLIS, MN

Mr. LAKIN. Thank you, Mr. Chairman.

My name is Charlie Lakin. For about 10 years now, I have been involved in research on long-term care for persons with developmental disabilities. Title XIX, and particularly the ICF/MR program, has been an unavoidable center of my attention. It represents over half of all federal expenditures for all services to people with developmental disabilities, and it provides three-fourths of all funds for residential services.

In short, it is the primary policy by which federal government participates in services for persons with developmental disabilities.

In my research, I have had an ongoing opportunity to judge this program in terms of my own values, but in developing my written testimony, I decided to look at the current policy in terms of the values Congress has espoused for persons with developmental disabilities. I found those values in the Developmental Disabilities Act of 1987.

Within the DD Act was a congressional finding that it is in the national interest to offer persons with developmental disabilities the opportunity, to the maximum extent feasible, to live in typical homes and communities. Yet, under present policies, about 85 percent of ICF/MR beneficiaries are housed in institutions of 16 or more residents. A substantial majority are in institutions of over 100 residents.

Within the DD Act, Congress expressed a commitment to assist people to achieve their maximum potential for independence. Yet the institutional settings in which Medicaid beneficiaries are concentrated are clearly inferior to community-based settings in the development of functional skills.

As a multiagency working group of the Department of Health and Human Services recently concluded, the findings of research are consistent and reflect important behavioral change clearly associated with movement from institutions to community-based living arrangements.

Within the DD Act, Congress expressed a commitment to promoting productivity among persons with development disabilities; yet current ICF/MR policy actually prohibits funding of vocational services.

Within the DD Act, Congress also expressed a commitment to promoting integration of persons with development disabilities. Numerous studies have compared social participation of institution and community residents. They consistently and clearly find community residents to be better integrated. They go to more restaurants, more stores, more movies, more sporting events. They go on more walks off the facility grounds. They visit more often with friends who live elsewhere. They are more likely to have friendships with non-handicapped peers. They have more contact with their own families. In short, they are better integrated in every conceivable way.

I really doubt that Congress often has a clear and consistent body of research from which to make its judgments that exceeds this one in terms of support for one position or the other. From that research, it seems clear that present policy needs major and immediate reform.

I believe the bill before you provides exactly the kinds of remedies required. It places reasonable limits on institutional expenditures. This will place modest pressure on states for continued deinstitutionalization, but it will also make states take a hard look at the inefficiencies of maintaining institutions operating far below capacity. It will greatly increase support to families.

The last major enactment of Congress of such importance in maintaining families was Public Law 94-142. Since its passage, from 1977 to 1986, the number of children and youth with developmental disabilities living in public and private residential facilities has decreased from 91,000 to 48,000. This bill would continue that trend.

It would involve the federal government in quality assurance, not only for ICF/MR facilities, but for noncertified facilities and alternative community services as well. As such, it would be the most significant improvement in federal quality assurance since the ICF/MR program brought federal oversight to public institutions.

It would increase access to services for tens of thousands of persons on waiting lists around the country whose families continue to reject the only openings now available, those in institutions.

Proceeding into the last months of the 100th Congress, there are only two choices before Congress. The first is to stick with the policy established in 1971 to make deplorable conditions in institutions less deplorable. The other choice is the bill before you which could do much to establish harmony between the values espoused by Congress and the programs available to reflect them.

I could quibble on little points in this bill. In fact, I have. But its good is enormous, and I can only urge its support in this Congress. As a researcher, a foster parent of a child with development disabilities, and even as a board member of a large private facility, I support this bill without reservation. It will be the most significant and beneficial legislation for persons with development disabilities since Public Law 94-142.

Thank you, Mr. Chairman.

[Mr. Lakin's statement appears in the appendix.]

Senator MITCHELL. Thank you, Mr. Lakin. You have set a commendable standard of brevity that future witnesses will be hard-pressed to meet.

Before proceeding to hear from our next witness, I would like to recognize our distinguished colleague, Senator Durenberger, who served with distinction as Chairman of this Subcommittee for six years. He is a national leader in this area.

Senator Durenberger, welcome. We will be pleased to hear an opening statement if you care to make one.

Senator DURENBERGER. Thank you.

I have an opening statement that I would like to submit for the record.

Senator MITCHELL. That will be done.

OPENING STATEMENT OF HON. DAVID DURENBERGER, A U.S. SENATOR FROM MINNESOTA

Senator DURENBERGER. In addition, I wanted to get here to introduce Charlie, but he has done it himself. That was a terrific statement, particularly some of the parts you didn't get to that concern a lot of us; that is, the federal role and the way in which the federal government participates in the financing through SSI and SSDI, or the inadequate way in which we participate.

Those of us who are going to be dealing in long-term care as it is commonly thought of in terms of frail elderly and so forth, would do well to see what role public financing is playing in, say, nursing home care at $65, $75, $85 a day for the frail elderly, and the wide gap between that and the same kind of commitment that the public resources make in the area of care for those with development disabilities. It is too large a gap, but it often represents a gap in our society between commitments we have made to the various generations, and I hope we are all going to work together to narrow that gap, Mr. Chairman.

Obviously, each year when we go through this hearing, we get closer to a solution, and I need to compliment my colleague, John Chafee, who has been reminding us of our responsibilities here since I got here in 1979. Each year I think we sit at one of these hearings, and each year we get much closer, and each year we find that Charlie Lakin says it is time to move.

So I thank you, Mr. Chairman.

Senator MITCHELL. Thank you, Senator Durenberger.

Ms. Bradley, welcome. We look forward to hearing from you.

STATEMENT OF VALERIE J. BRADLEY, PRESIDENT, HUMAN SERVICES RESEARCH INSTITUTE, CAMBRIDGE, MA

Ms. BRADLEY. I am very, very excited to have the opportunity to make a presentation to you this morning. As Charlie has said, this legislation really represents values and goals that a lot of us have been working towards for a good number of years.

There are three things very quickly I would like to cover this morning. First, I would like to talk about the results of the Pennhurst study. Secondly, I would like to talk about quality assurance. And thirdly, I would like to touch on some issues affecting families.

First, the results of the Pennhurst study, the findings of which significantly underscore the objectives in this legislation. For five years I was co-director of a study that was funded by HEW to look at what happened to people who left Pennhurst State Center in Pennsylvania as a result of a federal court order.

The findings really do underpin a lot of the objectives of this legislation. Briefly, what did we find? First, that people who moved to the community showed growth in adaptive behavior 10 times greater than the growth of those persons who remained at Pennhurst.

Secondly, before people left Pennhurst, families, about 72 percent of them, were opposed to placement into community settings. After the placement, virtually all families were positive about their families' placement in the community.

The costs in community settings were less than those at Pennhurst and more service, more importantly, was delivered for the dollar spent in the community setting.

Finally, community homes rated significantly higher on scales of normalization and individualization.

These findings have been replicated in New Hampshire, Connecticut, and Louisiana. They shouldn't be taken out of context, however. It is important to remember that in the states where these findings were uncovered, there was a strong administrative and oversight mechanism in place, and I think the legislation before you recognizes these requirements.

It mandates, for instance, an independent case management system, competency base personnel standards, very clearly programmatic expectations, individualized planning, and a framework for quality assurance.

Quality assurance, an area where I think the legislation really breaks new ground, to underscore what Charlie has already said, quality assurance is critical to the success of community programs. The bill before you, I believe, really embodies all of what we know to be the key ingredients in quality assurance systems.

First, it doesn't assume that quality assurance is just a unidimensional activity. Therefore, it includes not one, but several different techniques for assuring that people are better off, including federal oversight and validation, state licensing and accreditation, an independent third party of review of outcomes, a case management system that is independent from service provision.

The law also includes the public, families, and clients in the quality assurance system through family monitoring and assessments of consumer satisfaction and broad participation in standards setting.

The bill in my judgment meets all the objectives of quality assurance. It ensures capacity, it ensures best practice through licensing and through the review of individualized client plans. It ensures cost/benefit through the establishment of a decent information system.

Most importantly, it requires an assessment of whether or not people are better off as a result of receiving services.

Finally, the legislation includes very strong protection for the rights of people and their families through some impressive provisions of grievance and appeal procedures. It includes a protective intervention service and also rightly includes a protection and advocacy system as a key player.

The bill explicitly requires 60 days' notice before anybody is placed into a community setting.

Finally, a few words about families. I would like to say a good deal more, but I realize I have to be brief. Until recently, families who had children with developmental disabilities were afforded really only two options. They could place the child out of the home in an institution or they could provide home care with very little external support.

Recently we have begun to realize that families need supports to enhance their care-giving capacities. However, the current system for these families is still very fragmented and inadequate. With respect to one of the federal programs for children with severe health disabilities, the Model 50 Waiver program, there are only 18 states participating, and in those states that do participate, in many instances there are very few families.

A failure to recognize the role that families play in providing care in the home has serious financial consequences. For instance, in a recent study, it was shown that there is a savings of approximately $40,000 per month for babies who were being fed through various kinds of technology who remained at home and out of hospital settings.

The proposed legislation recognizes the uniqueness of families and provides a flexible menu of services that will empower and not supplant families and their natural support systems. I would, however require that the waiving of parental income, the waiving of the deeming of parental income be made mandatory and not optional.

I strongly urge your support of this legislation.

Thank you.

[The prepared statement of Ms. Valerie Bradley appears in the appendix.]

Senator **MITCHELL**. Thank you, Ms. Bradley.

We are now pleased to hear from Mr. Welch. Welcome. We always enjoy having witnesses from Maine before this panel, and we look forward especially to hearing from you.

STATEMENT OF RONALD WELCH, PRESIDENT, NATIONAL ASSOCIATION OF STATE MENTAL RETARDATION PROGRAM DIRECTORS, INC., AND ASSOCIATE COMMISSIONER OF THE MAINE DEPARTMENT OF MENTAL HEALTH AND MENTAL RETARDATION, AUGUSTA, ME

Mr. **WELCH**. Thank you very much, Senator.

Senator Mitchell, Members of the Subcommittee on Health, good morning. My name is Ronald Welch. I am the Associate Commissioner of the Department of Mental Health and Mental Retardation in the great pine tree State of Maine.

I also serve as the President of the National Association of State Mental Retardation Program Directors, and appear before you today representing the designated state officials who are directly responsible for the provision of services to a total of over half a million children and adults with developmental disabilities.

During the last decade, an obvious and profound change has taken place in how services are provided to individuals with developmental disabilities. If we have erred historically in how we have served persons with mental retardation, it is in that we have consistently underestimated their ability to learn, to grow, to lead happy and productive lives.

By providing a responsive array of community-based, residential, habilitative, and support and employment opportunities, we have begun to correct that error. But while this change is real and is evidenced in the fact that state governments have increased their expenditures for community-based services by 484 percent since

1977, the equally obvious reality is that the federal Medicaid program, which now finances $2.9 billion for services for persons with developmental disabilities is not in concert.

In attempting to understand the magnitude of the need for Medicaid reform and the extraordinary promise which the Medicaid Home and Community Quality Services Act of 1987 offers, it helps to make things concrete.

A young girl named Carla was among the children I was assigned to care for as a ward aide at Maine's Pineland Center 20 years ago. She was nine years old then, unable to speak and unwilling to make eye contact. Her arms and legs were completely covered with tiny infections and scars from self-inflicted pinching.

Today, several years after Maine became the first state in the nation to fulfill the promise of a major federal court order consent decree, Carla is now a young woman who lives in a small community group home in rural Maine, attends day program, and enjoys a quality of life which all of us in this room would want for those children and adults for whom the federal Medicaid program now pays $2.1 billion for services in large public and private institutions.

The Medicaid Home and Community Quality Services Act of 1987 has the strong support of the National Association of State Mental Retardation Program Directors. Our support for this legislation is based on a careful analysis of the implications of the bill and a recognition that it would rectify many of the fundamental defects in current Medicaid policy.

More specifically, Senator Chafee's bill would:

(1) Eliminate the institutional bias inherent in Medicaid law and thus place community and family support services on an equal footing with institutional care.

(2) Grant the states greater flexibility in using Medicaid funding to provide services which are based on people's needs rather than on ineffective and fragmented policy.

(3) Shift the emphasis of Medicaid funding toward habilitation services that assist individuals with severe disabilities to achieve greater independence and assure productive roles in American society.

(4) Provide families with expanded incentives to choose home-based care.

(5) Build upon the experience of the Home and Community Care Waiver program by providing states with greater flexibility in designing and financing out-of-home care services.

While we wholeheartedly endorse Senate bill 1673, there are several provisions of the bill which we believe should be modified:

(1) Limit the maximum age of onset of a qualifying disability to 22. This bill is basically designed to restructure Medicaid as it impacts on persons with developmental disabilities. This intent should be sustained.

(2) Allow states who provide direct services to also provide case management at local, county, and state government levels, as long as they can assure that it will be done without conflict.

Taken as a whole, the Medicaid Home and Community Quality Services Act of 1987 offers an unprecedented opportunity to make federal law affecting persons with developmental disabilities compatible with sound and accepted social policy. We have confidence that you, our Congress, will be responsive to this opportunity, and I personally have trust that under your fair and guiding hand, Senator Mitchell, this opportunity will not be lost.

[The prepared statement of Ronald Welch appears in the appendix.]

Senator MITCHELL. Thank you very much, Mr. Welch.

We will now proceed to questioning by the Members of the Committee. Under the Committee's rules, each round will be five minutes, and the questioning will occur in the order that the Senators appeared for the hearing. So we will begin with Senator Chafee.

Senator CHAFEE. Thank you very much, Mr. Chairman.

I want to thank each of the witnesses.

Let me address the panel as a whole. There are those who say that the research that has been done—and I am referring especially to the Pennhurst study, but also to others—will say that is all well and good, except that doesn't deal with the severely or profoundly retarded; that you are just skimming, as it were; you are taking the easy cases and how they have thrived when they have been out of an institutional setting.

Do you have anything to counter those charges? Can you cite some research that deals with those who are severely or profoundly disabled?

Why don't we start with Ms. Bradley, and then I would like to hear from each of the rest of you.

Ms. BRADLEY. Appropos of Pennhurst, the majority of people who were moved out of Pennhurst—and now that is virtually everybody—had severe and profound disabilities. I would venture to say that perhaps the only group that was under-represented were individuals who had very severe medical complications, who might have been on some kind of technology to keep them alive.

But, short of those individuals, there were very large numbers of people with very profound disabilities moved into the community. Likewise, in New Hampshire, Senator, people out of Laconia State School. Likewise, in Connecticut, et cetera.

So I don't think that is true.

Senator CHAFEE. Mr. Welch?

Mr. WELCH. We recently completed a study funded by the Health Care Financing Administration of our community-based waiver program. This was of a program that focused as much on people with profound and severe mental retardation as other people who enjoyed services in the program.

The results were very positive. People made positive gains and in many ways these were people who were twins, if you will, of folks still residing in the state institution at Pineland Center.

Senator CHAFEE. Mr. Lakin?

Mr. LAKIN. Well, I could only agree with them. Over the last year, I have worked as a consultant to the Department of Health and Human Services, looking at Medicaid policy. One of the issues that the persons working on this working group were concerned with were the effects of institutional versus community placement.

The research that I was able to locate for them—and it is a considerable body of research—was sufficient for them to conclude that the findings are consistent and clear that institutional care is to be avoided for all persons if one is interested in developmental outcomes.

I think the point that can be made, too, from my perspective as an educational psychologist. People with severe and profound disabilities have the least ability to generalize. So if we start with the assumption that these are people who are members of our culture and have the right to learn the ways of our culture, those ways must be taught in the culture. There is no way that these people can infer from lessons taught in an institution, how to live in the communities of our country.

Senator **Chafee**. I would like to ask you a second question. The opponents of the legislation will say, very clearly, we agree totally with you that deinstitutionalization is fine, but we don't want any restrictions on the amount of funding for institutions. We believe in a choice.

And the word you will hear throughout the testimony I believe today will be "choice." We believe in choice as much as you do. So therefore, keep the present system going. It provides a choice. And don't put any restrictions, as this legislation does, on the funding for institutions. There is level funding for the institutions in that inflation is not added, except if it is above 6 percent.

Now, what are the arguments for the legislation putting a freeze, if you would, on institutions? Why not just keep the present system going?

Mr. Lakin?

Mr. **Lakin**. I have followed institutional populations for quite a while now, and they are decreasing at a rate that is sufficient to absorb most of the problems that would be associated with the cap.

I think the other problem is that institutional care is often done in such a dumb way that if people would just take out certain components of it that are done in a most silly way, that it would put no financial pressure on institutions.

I will give you an example. Yesterday I was at an institution in Ohio, a small institution, but an institution. It looked like an institution. They had one program of transition for persons who were going to be moving out of that institution—in a house, on the grounds of the facility.

Now, if that institution wanted to run that program well, they would close down the house on the institution, and take the money and the program off campus. With the decreased costs of running that program on campus, they would be able to cover whatever inflationary pressures lowered their real dollar per diem for the nontransition programs for many years.

There is room to work within that cap. It is a very generous cap. And, as you know, it has come about through years of compromise. It is reasonable.

Senator **Chafee**. My time is up, Mr. Chairman. I might get back to this later.

Thank you.

Senator **Mitchell**. Thank you, Senator Chafee.

I would like to address a question to all of you and ask you to briefly respond. Many of the opponents of this legislation contend that not all developmentally disabled persons can benefit from placement in community-based facilities. There are some persons, depending on the severity of their condition, depending upon how long they have been in institutions, middle-aged persons who have spent their entire lives in institutions, who will not be able to function in a community-based facility.

Do you acknowledge that there are at least some persons who should remain in institutions as opposed to community facilities, or do you believe that all persons in such circumstances could benefit?

Mr. **Welch**. Senator, I would be pleased to take the lead on that. It is my assessment that the issue isn't where people are served, but how they are served. What services do they receive?

And there have been ample cases cited where people with very severe disabilities can be cared for in a very productive way in settings outside of institutions. As I cited, there are ample examples of that in the State of Maine.

I think the dichotomy, though, of institutional versus community to some extent is a false one. We really ought to focus on what services people need.

Ms. **Bradley**. I think we also ought to think more clearly about what we mean by benefits. One of the benefits certainly of being in a smaller home in the community is being able to interact with that community, being integrated into the normal and regular life of that community, something that is virtually impossible in a large institutional setting.

So I think it really has a good deal to do with how we think about the goals for people with development disabilities, and obviously if integration and normalization are crucial goals, which I think we all on this panel believe, then that goal can only be realized in a setting that is small and normal and homelike.

Senator **Mitchell**. Mr. Lakin.

Mr. **Lakin**. I believe very firmly that there is no purpose for institutions as we know them today, and that in 25 years we will have recognized that, and that era will be long behind us.

Senator **Mitchell**. Mr. Welch, in her testimony, Ms. Bradley described a circumstance in the Pennhurst study where a majority of the families who initially opposed the movement to community-based facilities later, after the experience, came to support it.

In Maine, there has been a similar movement which you described. What was the reaction of families there?

Mr. **Welch**. Initially, on the part of some parents, concern was expressed about what would happen if community placement occurred. Our approach was to work with them on a family-by-family basis. Over time, through actually experiencing what community life meant, opposition has basically dissolved.

So I think handling it on a very personal level and assuring parents that their involvement in what Val calls "quality assurance" is part of what needs to occur.

Senator **Mitchell**. Mr. Lakin, in your testimony, you cited a substantial cost savings between persons in the traditional ICF/MR program and those in the Medicaid Waiver or community-based programs.

How do you account for the difference in costs?

Mr. **Lakin**. Only about two-thirds of the people in the Medicaid Waiver program are in any kind of residential care at all. They are persons living at home, who receive some services, but not what we might call a total service package.

Many of the people receiving waiver services are in foster care. Foster care around the country averages around $23 a day. State institution care today averages about $140 a day. It doesn't take long to add up savings when you are involved in that kind of differential.

But I think we can overdo the cost part, I really do. One can put together a program in the community that costs as much as a program in the institution. The issue is, what do you get for what you pay? And, believe me, you don't have to spend long in the state institutions of this country to believe you don't get much for what you are paying.

I just think that ought to be the bottom line for the Senate Finance Committee. It is a bad buy.

Senator MITCHELL. Thank you very much, gentlemen and Ms. Bradley. I have several additional questions which I will submit to you in writing. Other Senators who are not able to be present may also have some questions after reviewing your testimony. That will be the case with all witnesses. And if you do receive written questions following the hearing, we ask you to respond in writing at your earliest convenience.

Mr. LAKIN. Mr. Chairman?

Senator MITCHELL. Yes.

Mr. LAKIN. Last night about 11 o'clock, I got a call from Lynn Honeycutt who works at a place called Wheel House. It is a program for persons with severe disabilities in Lakeland, Florida. She asked me to stop by Senator Chiles' office this morning and pick up some pictures to share with the Committee.

These are pictures of a program that presently operates without Medicaid funding. It is a program that has to raise about 50 percent of its total budget from private contributions. And she wanted to know if it would be possible for me to pass on those pictures to members of the Committee to show some of the people and programs that Senate bill 1673 would help.

Senator MITCHELL. It certainly will, and we will be pleased to receive them and any other information that you or she wish to provide. Thank you very much for your testimony.

Senator CHAFEE. Mr. Chairman, I think you are right. We do have a long list of witnesses and I think it is best to move along. I will also have several questions that I will submit in writing.

One of them, Mr. Welch, refers to your testimony on page 10, dealing with the amortization. We will send that to you and will appreciate if you could answer.

Thank you, Mr. Chairman.

Senator MITCHELL. We are pleased that Representative Bartlett has been able to join us now.

Good morning, Representative Bartlett. Welcome. We will be pleased to hear your testimony.

STATEMENT OF HON. STEVE BARTLETT, U.S. REPRESENTATIVE FROM THE STATE OF TEXAS

Representative BARTLETT. Thank you, Mr. Chairman.

Mr. Chairman, I do apologize to the Committee for not having been here earlier. The President was on the House side this morning in a briefing with the Republican conference, and since that is not as frequent an occurrence as ought to happen, I needed to stay for that.

Mr. Chairman, I come here today to express my own support, after having worked with these issues for the last couple of years on the House side, for S. 1673, the Medicaid Home and Community Quality Services Act.

That support has been growing for this legislation on the House side, so I am joined today by an additional 146 of my House colleagues who have co-sponsored identical legislation, introduced by Congressman Florio in the House.

Mr. Chairman, I would note that the support in the House, as in the Senate, cuts across party lines, represents a wide range of political philosophies on other issues, and represents an extremely broad coalition of members from all sections of the country and all political philosophies and parties.

Mr. Chairman, I would also note, I have served for the last five years as the Ranking Republican on the Select Education Subcommittee which deals with both vocational rehabilitation and with education of the handicapped directly, and indirectly with these issues in Medicaid and other issues, because all of the federal issues involving disabled persons are in fact related from the perspective of that person.

Mr. Chairman, it has been my conclusion that S. 1673 will make a significant contribution towards the goal of assisting persons with disabilities to live as independently as possible. The way it accomplishes that is to provide additional and emerging options to live independently in community settings.

This legislation essentially achieves two goals. It provides opportunities for those disabled individuals to choose to live in those community settings on the one hand, and on the other hand it does respect the choice of those families who place their disabled family member in large congregate residences, and doesn't set down to close out that option.

My decision to support this legislation was not made lightly. Along with others, I had declined to support similar legislation in last session and previous sessions because prior legislation had imposed unrealistic and, to some anyway, frightening mandatory reductions on supports to institutions. Yet the current system of Medicaid support is not satisfactory, and I concluded it was not satisfactory because it does not provide equitable support to small community-based settings.

Current law, in summary, is severely biased towards residents living in what are called intermediate facilities for the mentally retarded, or large institutions. The majority of those ICF/MR approved facilities are large institutions.

S. 1643 eliminates this inequity by placing a ceiling on funding of ICF/MR programs at current levels. That ceiling thus does not threaten the provision of services that are provided to persons in institutions, because the number of individuals placed in institutional settings is being reduced in some states rather dramatically and in other states on a gradual basis.

The experience in my own State of Texas is a good example of the interaction between the ceiling, the state policies, and the security and quality of services for individuals who will continue to reside in institutions.

Texas is currently in the middle of a six-year strategic plan, whether or not this bill passes, that would dramatically reduce the size of its institutional population. Two years ago, the State of Texas had 10,000 persons with disabilities residing in institutions. Last year, that population was reduced to 8,200 and the target for the end of 1988 is 7,200.

The State is actively assisting in the placement of those individuals who are moving out of institutions and into community settings. Texas has engaged in this process because of our belief in both the financial and the quality of life benefits of community living.

While the State recognizes that there are those individuals for whom an institutional setting may continue to be appropriate, the trend is towards creating increased community-based options. The ceiling, then, in this bill plays a constructive role in one other factor, and that is in containing cost.

The Congressional Budget Office has indicated that in the initial years following enactment, the bill will actually save funding and then in the sixth, seventh, and eighth year as additional options for community settings are opened up, the bill's cost will be approximately $300 million per year. The initial savings is attributable to the containment that will be placed on the current program's growth rate. According to the CBO, the ICF/MR program growth rate is approximately 12 to 14 percent per year, compared to a 10 percent growth rate for the entire Medicaid program.

The real savings, Mr. Chairman, comes from a factor that is not even measured in these figures. The real savings, it seems to me from having visited with residents of community settings, comes from the increased independence and employment opportunities that those residents enjoy.

The fact of the matter is that that is the key to the lock. That is the secret to providing additional choices, as well as containing costs, and that is to provide residential settings which give those residents the opportunity to obtain employment.

The fact is that this bill will lead, then, to increased financial and personal independence. On behalf of the clients themselves, S. 1673 will make that contribution in helping disabled people to receive the training and the assistance they need and the residential independent living setting that they require in order to just simply get a job and then to live independently, or more independently, federal financial cash assistance.

The federal government spends billions of dollars each year towards that goal already. Our vocational rehabilitation and special education systems are oriented towards placing persons in the community with the skills they need to function and work independently, but once that education or rehabilitation is completed, then the current Medicaid system tends to lock those persons into an institutional setting where their education and their vocational skills are both unnecessary and wasted.

By making Medicaid funds available to support community-based residences, then, S. 1673 will complement other congressional efforts aimed at employment and independence for persons with disabilities.

I support this legislation. I believe that these hearings will provide answers to many questions which are legitimately raised.

Senator Mitchell, I do commend you for holding these hearings. Many of these subjects have needed to be aired for some time, and for the questions that you have asked to try to get the questions and the answers out on the table.

It is my hope that the Medicaid Home and Community Quality Services Act will be passed this year. It can be passed; with this Committee's help it will be passed.

Senator MITCHELL. Thank you very much, Representative Bartlett, for your testimony.

Senator Chafee.

Senator CHAFEE. Thank you, Mr. Chairman.

Thank you, Mr. Bartlett, for that fine statement. We certainly will look to you for guidance on this measure in the House. We will work as hard as we can here in the Senate, and hopefully we can pass it this year.

We appreciate your taking the trouble to be with us.

Representative BARTLETT. Thank you, sir.

Senator MITCHELL. Thank you, Representative. We appreciate your coming.

The next panel includes Mr. George L. O'Donnell, Second Vice President, Voice of the Retarded, and President of the Wisconsin Parents Coalition; W. Robert Curtis, Associate Professor, New School for Social Research, testifying on behalf of the Congress of Advocates for the Retarded, Inc. of New York; and Mrs. Janelle Jordan, First Vice President, Association for Retarded Citizens of Texas, of Houston.

Good morning, Mrs. Jordan and gentlemen. Welcome. We look forward to hearing from you.

Mr. O'Donnell, we will begin with you.

STATEMENT OF GEORGE L. O'DONNELL, SECOND VICE PRESIDENT, VOICE OF THE RETARDED, AND PRESIDENT, WISCONSIN PARENTS COALITION, MILWAUKEE, WI

Mr. O'DONNELL. My name is George O'Donnell. I am testifying today on behalf of the Voice of the Retarded.

Senator MITCHELL. Bring that microphone up close to you so that the people will be able to hear you.

Mr. O'DONNELL. I am testifying today on behalf of the Voice of the Retarded, which is a group of parents, guardians, relatives, and friends of mentally retarded persons who reside in or are being cared for in over 50 public and private residential facilities throughout the United States.

In addition, we assist in coordinating 128 parent organizations opposing S. 1673. We express sincere appreciation to you, Mr.

Chairman, and to the Members of this Committee for the opportunity to testify at this public hearing.

We are here today, of course, to consider the merits of S. 1673, the stated purposes of which are to assist individuals with a severe disability in attaining or maintaining their maximum potential for independence and capacity to participate in community and family life.

Mr. Chairman, we believe that there is probably no person in this hearing room today that would disagree with the purposes of the legislation as they are stated here. Nevertheless, we oppose the enactment of S. 1673 because it attempts to attain its objectives by imposing upon a group of severely disabled individuals a mandatory deinstitutionalization program.

For instance, S. 1673 would freeze the Medicaid benefits of all severely disabled individuals who reside in or are being cared for in facilities of over 15 beds in size—not institutions—facilities of over 15 beds in size. Moreover, the terms of this so-called freeze are such that reimbursement for annual costs due to inflation would not be made.

Also, there are mandatory transfers. Under the terms of this legislation, all severely disabled individuals—and I use the term "severely disabled" individuals—this is not about only developmentally disabled persons—all these individuals would be transferred from large to so-called small facilities within a period of five years after its enactment.

Then we have, as Senator Chafee has mentioned, the issue of freedom of choice. Title XIX currently provides for qualified candidates to exercise freedom of choice with regard to the selection of services under the Medicaid program. However, under the terms of S. 1673, all severely disabled individuals would be denied this freedom of choice.

Then we have the question of standards in monitoring which was so eloquently addressed by one of my colleagues here this morning. We are familiar, of course, with the "look behind" surveys of intermediate care facilities for the mentally retarded. However, under the terms of S. 1673, the promulgation of standards, the monitoring of so-called small facilities, would be delegated to the states. Does the size of the facility give us cause to relax our concern for adequate standards and monitoring procedures? We think not.

In general, Mr. Chairman, these problematic provisions tend to create a huge controversial deinstitutionalization program which permeates the entire aspect of this bill. In other words, S. 1673 proposes to accomplish its stated objectives with regard to severely disabled individuals by converting Medicaid into a deinstitutionalization program. This approach is obviously counterproductive to the achievement of the more worthy objectives of this program.

Finally, just a word about costs, Mr. Chairman. In our opinion, there would be significant costs to implement this legislation and we are pleased to note that many Members of the Congress are prepared to support the allocation of sufficient resources to ensure the creation of a comprehensive program of services for all severely disabled individuals.

What do we propose? We propose that there be made available for all severely disabled individuals a comprehensive array of residential services, including group homes, including all types of small residential facilities, and including high quality intermediate care facilities.

Mr. Chairman, this is our position with regard to S. 1673. We would compliment Senator Chafee for bringing these issues before the Congress, because we feel they should have been discussed long since.

Thank you very much for your time, sir.

Senator MITCHELL. Thank you, Mr. O'Donnell.

[The prepared statement of George O'Donnell appears in the appendix.]

Senator MITCHELL. We will now hear from Mr. Curtis. Welcome, Mr. Curtis.

STATEMENT OF W. ROBERT CURTIS, M.P.H., Sc.D., J.D., ASSOCIATE PROFESSOR, NEW SCHOOL FOR SOCIAL RESEARCH, NEW YORK, NY, TESTIFYING ON BEHALF OF CONGRESS OF ADVOCATES FOR THE RETARDED, INC., GREENFIELD, MA.

Mr. CURTIS. Thank you very much, Mr. Chairman, Members of the Committee on Finance. I thank you for inviting me to speak this morning. I appear on behalf of the Congress of Advocates for the Retarded, a national parents organization.

Although I will give voice to the deep reservations held by many parents about S. 1673, I also speak from my own experience of 20 years in the field, including work as a clinician, as a manager of both public and private programs, and more recently as an educator.

I will limit my remarks to a single idea because of the five-minute limitation, not just because almost everything has already, or will today, have been said in one of the hearings or another. Rather, I want to address a single theme that has remained essentially the same throughout each version of this bill.

The federal government would have states phase out their institutions. Here is the idea: By encouraging states to phase our their institutions, you are asking them to breach a 150-year old covenant, one that hundreds of thousands of family members have come to rely on.

From my experience and research, there is no more important covenant between each state and its citizens than this. When a family is confronted with nature's cruelest blow and then sets out to raise their mentally disabled child, the state has until now said, "when you can do it no longer, we will take custody of your child. We will make the substituted decisions required by your family member. We will provide shelter, food, clothing, day care, health care, and other services as required. And we will use the best interest of the child standard when making substituted decisions."

I say "until now" because if this bill passes in its present form, the covenant will be destroyed. This is no small matter. The history of this covenant is moving beyond belief. It runs deepest for those families with only moderate means and a severely impaired child.

Listen to their profound ambivalence and personal stories before enacting a law that will destroy this covenant. Read the deeply moving records written by some of the professionals who picked up substituted decision making in each state institution over the past century and a half. Examine the legislative records that document the intent of the state when each new institution and each new building was created at that institutional setting.

Until recently, everyone understood this covenant. But now, with the deinstitutionalization movement still out of control, some professionals would have you replace this covenant with their own ideals and values.

Under this bill, custody of the mentally disabled family member will be transferred not to a state institution, but instead to an unstable and uncertain private sector. Substituted decisions will be made by individuals who are unaccountable to elected officials and largely out of reach of the Executive Branch of state government. Of course, these decisions will be even further removed from family members.

We know well that under this bill, economic considerations, not the best interest of the child standard will determine where and how the disabled family member is cared for. That is the nature of this mix of federal and state funding.

Family members will have little choice, not merely because the institution is gone, but because the private sector, as dispersed and scattered as it is, cannot effectively act on the best interest standard. Yes, it can take custody. And yes, it can make substituted decisions. But these decisions are out of sight and largely unaccountable except to financial criteria.

In conclusion, S. 1673 threatens to add a second injury to families who are already reeling under the harm dealt to them by nature. I ask that you not encourage states to breach this covenant. Instead, respect it. Your bill should use the covenant as a foundation for expanding services to the mentally retarded, not as a vehicle to breach it.

Senator MITCHELL. Thank you very much, Mr. Curtis, for your statement.

[The prepared statement of Robert Curtis appears in the appendix.]

Senator MITCHELL. Mrs. Jordan, welcome. We look forward to hearing from you.

STATEMENT OF JANELLE JORDAN, VICE PRESIDENT, ASSOCIATION FOR RETARDED CITIZENS OF TEXAS

Mrs. JORDAN. Senator Mitchell, Senator Chafee, Members of the Senate Finance Subcommittee on Health, my name is Janelle Jordan. I am the parent of a 24-year-old woman with severe mental retardation, autistic behavior, and a complex seizure disorder. I reside in Houston, Texas and serve as Vice President for the Association for Retarded Citizens of Texas. On behalf of the ARC/U.S. and Texas and our over 160,000 members, thank you for the opportunity to appear before you today in support of S. 1673.

But first let me tell you a little about my daughter Lisa. Until she was 17, Lisa lived at home with our family. As she reached adult size, it became extremely difficult to care for her and impossible to find support services.

Lisa attended a public school for only two years. The rest of the time she attended a private school, partially funded by the local school district, but which I located and to which I took her. Because of the severity of Lisa's handicaps, an institution seemed the only choice for her long-term care. Indeed, this was the only choice in Houston seven years ago, and for most it remains the only choice today.

Lisa resided at the Brenham State School, an ICF/MR program, for five years, 75 miles from our home, in a dorm with 27 other residents. I soon realized that Lisa was not receiving the supervision or training she needed. Lisa developed behavior problems and lost many of the skills she had when she entered the institution. With so many residents living together, the staff could not prevent or correct these problems.

During this time, I searched for a better solution for Lisa's care. I learned of programs in other states and found that persons as involved as Lisa were living successfully in small community-based family-like settings. With my local ARC unit, we built, furnished, and pledged to maintain a group home for six persons, obtaining operating funds only through the terms of a lawsuit and only for former state school residents.

Lisa moved into this home two years ago, only 10 minutes from our family. She has her own room, goes to a work activity program, attends church, sees our family doctor for routine problems and the Houston Medical Center for her seizure disorder and behavior problems.

Two staff persons teach Lisa and her friends personal hygiene, homemaking and meal preparation skills. Lisa especially enjoys having a kitchen again where she can assist during meal preparation and going into the yard whenever she wants.

Lisa has a home now like anyone else, and the training needed to become as independent as possible. But it all came about only through her family's and friends' efforts. Neither state nor local governments provided any assistance until forced by a lawsuit.

But there are thousands of Lisas still waiting, whose families have no resources and no choices. It is difficult for me to criticize a system that does have some caring staff whom I entrusted with my daughter's care and that, for Lisa and others, has been the only game in town. But when I look at this system honestly, I realize that a large institution did not help Lisa, and I don't believe it can help anyone.

For Lisa and thousands of her peers, we urge swift passage of the legislation before you today. Throughout the United States, there are well over 135,000 persons with mental retardation in need of services. In Texas, only 19 percent of the persons in need of services reside in large congregate facilities, but over 79 percent of funding is spent in large institutions, a scenario repeated throughout the United States.

A majority of funds are spent on a few persons, leaving thousands of persons underserved or not served at all. We are sure that Congress intended that Medicaid funding improve services for persons with mental retardation, but it has created a disincentive to the development of community and in-home and family support services.

Because Medicaid funding has not been available for such services as respite and attendant care, specialized transportation and adaptive equipment, the ICF/MR program has served to undermine the family unit. Faced with no other alternatives, families have been forced to seek out of home placements with its pressures on the family and extraordinary cost.

We are pleased that the bill not only provides a true choice for families, but through its quality assurance provisions ensures that persons receive effective as well as efficient services. By maintaining adequate funding for institutions, mandating a planning system for both institutional and community services, requiring an independent case management system and creating a stable source for community services, S. 1673 ensures that the dumping seen with the mental health patients in the 1960s and 1970s does not occur with this population.

For Lisa, for the thousands of Lisas across this country, and for all their parents struggling to maintain the integrity of the family unit, we urge this Committee to support passage of S. 1673 during the 100th Congress. To fail to act now condemns Lisas and their families to lives of continuing desperation.

Senator MITCHELL. Thank you very much, Mrs. Jordan, for your statement.

[The prepared statement of Janelle Jordan appears in the appendix.]

Senator MITCHELL. Senator Chafee.

Senator CHAFEE. Thank you, Mr. Chairman.

I want to thank each of the panelists for their contribution here.

Mr. O'Donnell, you raised a good point about the quality in monitoring. Do you have any suggestions how we might strengthen those provisions in the legislation?

Mr. O'DONNELL. Yes, sir; I do.

Under the present system of quality in monitoring as proposed under S. 1673, on page 23, line 21 of the bill, it makes it part of "state requirements" that states promulgate the standards and engage in the monitoring of the services.

Our experiences, of course, with nursing home monitoring have not been very encouraging when the states have done this. Then again, on page 70, line 6 of the bill, the Secretary of Health and Human Services is specifically not authorized to set standards for community services.

Senator Chafee, our suggestion would be that all services under federal funding and all services receiving services under Medicaid programming be required to meet federal standards and federal monitoring procedures.

Senator CHAFEE. You suggest—I think I have the words correctly from your testimony—making a true continuum of services available. Obviously that is what I am seeking here.

How do you suggest that we do it better? In other words, we know the present system. The present system, as so many witnesses have testified, Mr. Welch and others, has—and I think you will agree—a definite bias toward the institutional setting. I mean that is what Medicaid is, except for those states that have waivers.

How do we have this continuum of services available if we, as you suggest, reject this legislation which is the only legislation which provides for the encouragement of community-based care, respite care, foster home care, whatever it might be? If we just stay where we are and reject this legislation, obviously—at least it seems apparent to me—we do not have a continuum of services available.

Mr. **O'Donnell**. I am glad you asked that question, Senator Chafee, because if you recall, in 1962 I believe it was, the late President Kennedy issued the report, National Action to Combat Mental Retardation. That, of course, is where the phrase "a continuum of services" first came into being, and that continuum of services included not only the services, such as you so capably mentioned in the community, but also included very high-quality intermediate care facility services.

I might point out that I am not saying we should reject that aspect of the bill. I feel that as a result of this bill, we have a schism between large and small facilities. I don't think that is appropriate. I think we should have a continuum of services. I think we should have available an array of residential services, including group homes, including foster homes, and including high-quality residential facilities.

As a matter of fact, just last August in 1987, Professor Edward F. Zigler, a Sterling Professor of Psychology at Yale University, in accepting the Distinguished Service Award from the American Psychological Association, strongly endorsed the President's report, strongly endorsed the continuum of services principle, and said in effect that what should be available is an option of services from family care, extending all the way through to intermediate care facility services.

Senator **Chafee**. We certainly do agree on that. The problem is getting there.

Under the present existing restraints of funding, with a decided tilt toward the institutions, there is no incentive whatsoever in the states to move to this continuum of care with the way the Medicaid program currently is slanted.

I notice that my time is about up, but that is our problem. We don't address the challenges that Mrs. Jordan and the others have supported in the prior panel. We don't address those because you don't get the continuum of care because the money is all pouring through the Medicaid program into the institutions.

Mr. **O'Donnell**. We don't feel, Senator, that the solution of that problem is to impose a deinstitutionalization program on the severely disabled individuals who are currently residing in facilities of over 15 beds.

I would like to point out there is nothing, nothing whatsoever, in the Title XIX legislation that restricts Title XIX to over 15 beds. In fact, the largest growing segment of residential facilities today is in the area under 15 beds which are now being qualified for Medicaid funding.

So there is no bias to that effect. If there is a bias, it is in the failure to recognize the need for the same standards in the small facility.

Senator **Chafee**. Thank you.

Senator **Mitchell**. Thank you very much, Senator Chafee.

Mr. O'Donnell, you have heard testimony this morning from other witnesses who talked about the initial opposition to the movement from institutions to community-based facilities in various states, and each experience described the majority of parents and families were initially opposed to it, but after the experience occurred, they supported it.

Do you give any credence to those experiences at all?

Mr. O'Donnell. Senator, I certainly do. I have been very close to that program. One of our officers, as a matter of fact, has experienced that program and, of course, as you know, that is supposed to be an optional program. Section 1915(c) of Title XIX is an optional program.

I think what our panelists were stressing here is that it requires an agreement between the parents and the person who is proposing the placement, that the individual indeed will go to such a placement.

I would point out that not all of these placements have been successful. One of our panelists talked about the Pennhurst situation. I believe there are some serious questions today about that. As a matter of fact, there are some lawsuits that have been instituted in Pennsylvania, as I understand it, where those placements have not been successful.

But nevertheless, I do see the value of that. I think everybody in our organization sees the value of that. If there is an opportunity for anybody to reside in the community, that opportunity should be taken. But the freedom of choice principle should not be sacrificed to do that.

Senator Mitchell. Thank you, Mr. O'Donnell.

Mr. Curtis, you made a strong statement in opposition to the bill. As I understood your testimony, your reference to the instability and uncertainty of community-based facilities was based on the assumption that they are private in nature and therefore they are not public institutions and there is no accountability.

Is that the crux of your opposition? That seemed to be the thrust of your comments.

Mr. Curtis. In part. Smallness is the other variable.

Senator Mitchell. So if the community-based facilities were public facilities, then at least that portion of your argument would not be applicable.

Mr. Curtis. That is correct.

Senator Mitchell. Would you oppose the movement in any event? You said the other variable is smallness. Do you believe there is an advantage to size of institutions in terms of the quality of service they can offer?

Mr. Curtis. The two recommendations that I would make for changes in this bill are these: One, I would add a zero to the 16 bed limitation, so that states were permitted to create a stable institutional base for the most disabled. And at that decentralized location I would locate the public managers and those who do evaluation of the small programs so that they are not so far out of sight and out of reach of the government that funds them.

So I think, to answer your question, it is really a braiding together of the very small, tiny programs and the fact that they are being done under contract with the private sector, rather than directly by public employees who are directly accountable to the Executive Branch.

Senator Mitchell. In your remarks, you said very strongly that enactment of this legislation would destroy the covenant, which you movingly described.

Do you at least accept the premise that those who support the bill are trying to do what is right as they see it, and not making any effort to destroy anything, but rather to provide a quality of service in a manner that happens to disagree with yours, but nonetheless is as well motivated?

Mr. **Curtis**. Senator Mitchell, I believe that this is an unintended consequence of deeply held values and ideals, and I have the utmost respect for those values and ideals. But I believe that more careful thought needs to be given to the long-term consequences of this covenant that the state has now offered to its citizens for 150 years.

We are really not talking about a breach of that covenant that will happen in the next year or two, or three. We are talking about a decade into the 60-year life span or 70-year life span of a severely disabled child that is born today.

For that reason, I think we do need to examine this, terribly important covenant and the unintended consequences that this bill would have on it.

Senator **Mitchell**. Thank all of you very much for your testimony. It is very valuable and I am sure it will be considered carefully by all Members of the Committee.

Thank you very much.

The next panel consists of Mr. Jerry Klepner, Director of Legislation, American Federation of State, County, and Municipal Employees; and Mr. J. Gary Mattson, President, National Association of Private Residential Resources, and Executive Director, Exceptional Persons, Inc., of Waterloo, Iowa.

Before we begin, I would like to make a brief statement in behalf of Senator Harkin who wished to be here today in connection with Mr. Mattson's testimony. I would like to read this brief statement by Senator Harkin into the record.

"I am most pleased that Gary Mattson, a fellow Iowan, has been invited to be a witness on behalf of the National Association of Private Residential Resources as the Finance Committee holds a hearing on S. 1673.

"I greatly regret that I cannot be there this morning, because I am an original co-sponsor of S. 1673 and am committed to the principles that it stands for. I also regret that I cannot be there to introduce Mr. Mattson because I know how effective he has been in developing community-based, high-quality services for Iowans with developmental disabilities.

"Mr. Chairman, and Colleagues in the Senate, I am sure you will be informed by Mr. Mattson, and I hope your hearing proceeds well."

That is a comment by Senator Harkin.

We will begin now with Mr. Klepner.

STATEMENT OF JERRY D. KLEPNER, DIRECTOR OF LEGISLATION, AMERICAN FEDERATION OF STATE, COUNTY AND MUNICIPAL EMPLOYEES, AFL-CIO, WASHINGTON, DC

Mr. **Klepner**. Thank you, Mr. Chairman.

My name is Jerry D. Klepner. I am Director of Legislation of the American Federation of State, County and Municipal Employees.

Accompanying me this morning is Greg Devereaux, AFSCME's Coordinator for Health Policy.

I would ask, Mr. Chairman, that my entire statement be inserted in the record and I will at this time summarize the statement.

In addition to serving as AFSCME's Director of Legislation, I am also a Commissioner on the Virginia Statewide Health Coordinating Council and a Member of the Board of Directors of the Northern Virginia Health Systems Agency.

In these capacities, I am all too familiar with the real problems that have been created for the states with the Medicaid cutbacks that have taken place in the past few years, and I have been part of the process of trying to grapple with those cutbacks and still maintain a quality health system within the State of Virginia.

We would like to associate ourselves with the statements of Mr. O'Donnell and Mr. Curtis. I think that they reflected the position of AFSCME when they testified, as well as the position of their organizations.

Our primary problem with the legislation is the fact that large institutions have been the backbone of delivery of services for the developmentally disabled. We feel that the bill under consideration by the Subcommittee this morning would eliminate, through deinstitutionalization over a period of time, the effective role that large institutions play in the process of providing necessary services for the developmentally disabled.

We feel that the bill is tilted too far against the institutions and too much toward community-based services. Large institutions must remain an integral part of the continuum of service that is provided these individuals. They perform an essential role, that would be severely reduced by the legislation that the Subcommittee is holding hearings on.

We have other problems with the bill as well. We feel that the legislation would arbitrarily limit facility size, thereby restricting access for some individuals to a larger facility, which for them might be the most appropriate environment.

Under the bill, states would be allowed to establish their own rules and regulations to monitor the quality of newly created community services. Existing federal ICF/MR regulations would not be applicable to these new services. In effect, the legislation would provide for no federal role nor guidelines for the community-based institutions.

We are very fearful of simply turning over this important area to the states and the patchwork network of regulations that would be adopted by the states.

Also, we are concerned that S. 1673 minimizes the role of parents concerning decisions affecting their disabled offspring. And, finally, under S. 1673, if a facility closed, skilled, experienced human resources would be displaced and they would not be redeployed into the new community system.

Because we oppose S. 1673 does not mean that our union is in opposition to any Medicaid ICF/MR reform. We believe that certain reforms are necessary and should take place but they must be developed in a very thoughtful and responsible manner.

There are states—Massachusetts, Minnesota, and Senator Chafee's State of Rhode Island—which are excellent examples of the types of program that we feel we could work with the Subcommittee in the future to attempt to design. These states provide for state-operated continuum of care. In each of these states, both severely developmentally disabled individuals and workers have successfully moved into the community under the auspices of the state. State operation in the community will ensure access to care, accountability, and continuity of care.

Parents and relatives of the disabled support the emphasis in such a plan on permanence and constant supervision. Higher staffing ratios and lower worker turnover should similarly be embraced by state administrators and advocates.

Our members—and I will conclude in one minute—are eager to address the challenge of providing quality care to the developmentally disabled in the future. Through state operation of institutional and community services, we believe the developmentally disabled will be guaranteed the care they so urgently need and deserve.

Senator **Chafeee** [presiding]. Thank you very much, Mr. Klepner. We really have to stick to the time limit. If we let one go, the others will want it. And the others have been pretty good, so I will have to call you there.

[The prepared statement of Jerry Klepner appears in the appendix.]

Senator **Chafee**. I thank you for your testimony and we will go now to Mr. Mattson, please.

STATEMENT OF J. GARY MATTSON, PRESIDENT, NATIONAL ASSOCIATION OF PRIVATE RESIDENTIAL RESOURCES, AND EXECUTIVE DIRECTOR, EXCEPTIONAL PERSONS, INC., WATERLOO, IA

Mr. **Mattson**. Good morning, and thank you for giving us an opportunity to testify today about Medicaid reform legislation being considered by this Subcommittee.

I am Gary Mattson, and serve as President of the National Association of Private Residential Resources, representing about 650 agencies, private, nonprofit, and proprietary organizations in 49 states that together serve more than 40,000 people with disabilities.

Our Association members are strongly supportive of Medicaid reform that will enable more Americans with disabilities to live in their own homes and in small community living arrangements. There is much in this bill that we support, but we also have some concerns about its current form and hope you will give careful consideration to the recommendations in the printed testimony that we are submitting.

I would like to tell you something about myself and my agency to give you an idea of the kinds of experiences our members have and to demonstrate our knowledge about the needs of persons with disabilities.

I have worked in the field of mental retardation for 26 years, six of which were spent at the Woodward State Hospital School. Since 1968, I have worked at Exceptional Persons, Inc. and serve as its Executive Director. We operate a multipurpose agency. EPI began its residential program in 1969 and now has more than 200 individuals in residential services in 49 different scattered settings. Our largest homes are for 10 people.

In the next 15 months, we will be opening 13 more homes, each for five or fewer people. We serve persons who are mentally retarded, physically disabled, dually diagnosed with both mental retardation and mental illness, and people with traumatic brain injury.

Since 1980, not many Iowans have moved to the community from the two state institutions. More people should have a chance to return to their rightful place in their communities.

EPI does not currently operate an ICF/MR. That is in part because state ICF/MR rules have outmoded costly construction requirements. It would cost approximately $1,000 per bed to bring the Iowa group homes into compliance with federal ICF/MR rules. However, it would cost approximately $8,000 per bed to meet current Iowa ICF/MR rules with their inappropriate medical orientation.

With Medicaid reform, Iowa could begin converting group homes into ICF/MR and to access Medicaid funding for a variety of community-based services and at less cost. Two of the homes EPI is opening this next year will return people from Woodward to the community, people with dual diagnoses of mental retardation and mental illness, all of whom exhibit acting-out behavior.

While it costs $164 a day to serve these people at Woodward, it will cost just $80 per day in the community. Hopefully at some time in the future, these people will be able to move into less intensive, therefore less costly residences.

In large environments, many different employees work with each client. Our agency is able to bring more consistency into the lives of people who have severe disabilities. The homelike environments help to reduce inappropriate behaviors. The longer an individual has lived in an institution, the longer it takes to reduce those behaviors.

We want to serve more people in the community, both by bringing some home from the institutions, and by preventing institutionalization of others. What we are doing is done successfully in the community by many private agencies across the country. Maine and Minnesota are but two examples of states that have exhibited particular success in the development of excellent community programs.

Medicaid reform is a must. We must remove the institutional bias in the Medicaid program so that we can serve people within their community. This can be accomplished only with careful joint planning of the public and private sector to assure that transfers are handled appropriately and that movement is truly based on individual preferences and needs.

Quality of life and community integration play a much more important role than size. Under the present service configuration, there are just not enough resources to serve all of those who come to us for help. Medicaid reform would enable us to serve many more people in more appropriate settings, in less expensive ways. It could also allow us to provide more services to those now living in the community.

We encourage this Subcommittee to work actively on the development of legislation that will reform Medicaid so that it can support people in the environments that will enhance individual self-dependence and productivity.

I can't help but make one comment in response to statements made by an earlier speaker: that God has, over time in dealing with his chosen people, modified his covenants. I think at times also in history, that the federal and state government must review its covenants and make sure that they are adjusted according to the needs of the people that we serve.

[The prepared statement of Gary Mattson appears in the appendix.]

Senator CHAFEE. Thank you both very much.

Mr. Klepner, I would like to address a fundamental problem we have got here, it seems to me. That is, there isn't a witness who hasn't said we must have a continuum of care.

Whether you are talking Mr. O'Donnell or whoever it might be, they all support the idea of having the group home. I don't think there is a single person here who will say, we should never have group homes; everybody should be in an institution.

The problem comes with the fact that Medicaid—set aside waivers—Medicaid is an institutionally-oriented program. That is a fact. It does not provide for somebody being in a home. It doesn't provide for foster care. It doesn't provide for what we call a community setting. It provides for institutions. That is what it is. It is a medical program. That is what Medicaid means, as you well know.

So how do we go about—what encouragement can there ever be toward providing this continuum of care under the present system?

Mr. KLEPNER. Senator, let me answer your question, if I may, this way. I would like to do it outside of the context of the federal budget and dollars that flow to Medicaid.

The problem we have with the bill is that the bill, because of the funding freeze and the limited circumstances under which additional funds could flow to institutions, is tilted very much against institutions. Ultimately, we fear the death of large institutions under this legislation.

There is no question that under a system for developmentally disabled, you need to have a large institutional role. So the basic premise of the bill is one we disagree with.

I think there should be community-based facilities, public community-based facilities also available to individuals. We have a great deal of concern with simply having private sector community-based facilities.

Senator CHAFEE. Let's accept your philosophy. I will set aside Mr. Mattson's point, just for now, and advance on your theory that there should be hopefully AFSCME employees in each of the private homes, run by the state, with federal supervision, a stronger federal role and guidelines as you asked for. Everything you asked for, except it doesn't qualify for Medicaid today.

Now, how do we get from here, the institution, to where we are trying to take care of the individual, the disabled individual. And I don't think you are suggesting 100 percent of those who are currently in institutions should permanently remain in institutions. You are not saying that, are you?

Mr. KLEPNER. No, I am not.

Senator CHAFEE. So therefore, let's say some. I believe 100 percent. But let's say you say 50 percent of those in institutions would do better in a smaller setting.

Okay. How do we get there under your proposal? You reject my bill. We stick with the present system. How do we get there?

Mr. **Klepner**. The first thing I would do is, not create a disincentive with regard to the funding for the institutions, I would keep and, if at all possible, improve the funding for the institutions, and also have funds available under a carefully crafted, federally mandated program for community-based facilities. And I would do so with very strict guidelines in terms of the types of services that must be offered and the types of individuals that must provide the services.

I would do it in a carefully controlled environment. And we have some states, I think, that you could look to as an example of a system that works. And from our experience, Senator, looking toward your own State of Rhode Island is not a bad place to start.

Senator **Chafee**. Now, don't get too deeply into that, Mr. Klepner, because I know something about that.

Our major institution is going to be closed out. And that is pursuant to court order. The State is moving ahead of that. So don't put our State on as an example of somebody who is keeping an institution. That institution will be gone in two to three years, perhaps by the end of the decade. So I don't want to pick on you on that, but that is an area that I know something about.

So the problem is, Mr. Klepner, as you well know, Medicaid isn't an entirely funded federal program. You have to have state funds. And the state isn't going to leap in there with 50, 45, 55—whatever it might be—percent of Medicaid, willy-nilly, just because the federal funds are there.

So unless we have something to push the states into going into this area of community-based care, we are just plain not going to have it, in my judgment.

Mr. **Klepner**. If our choice, Senator, was this bill or the status quo, with reservations, we would support the status quo.

Senator **Chafee**. Don't be so reluctant. Put more enthusiasm into it, Mr. Klepner.

Mr. **Klepner**. We feel that, as I said, the very basis of this bill is in the wrong direction. Now, once again, without proposing any specific solution, because I don't think that that is necessarily my role, but I feel that there is experience in the states—and I will stay with Rhode Island, even in light of what you mentioned with regard to the large institution. I would also look at Minnesota, I would look at Massachusetts, as states where there has been an effort toward community-based services under a continuum of care or continuum of service environment.

We think that is absolutely crucial. I am not certain, Senator, that we can, given the Medicaid funding problems, leap from where we are now to where your bill would go.

Senator **Chafee**. I don't agree with that. I think we do have to advance on the assumption here that there is not going to be a great big new pot of money suddenly available from the federal government for Medicaid. As I understand your proposal, it is keep the state institutions. Keep them filled up as they currently are, and then have more federal money come in, more Medicaid, which the states presumably will enthusiastically match, to take care of the waiting lists of others who might want to go into group homes.

But that isn't realistic, I don't think, Mr. Klepner, certainly under the financial environment that exists now. I tell you, we are lucky we don't get a freeze on Medicaid. Indeed, the Administration has proposed it in past years, as you know. I fought against it and succeeded. It is an entitlement program, but it is under constraints.

Let me just say something. So many people here have said this program, this legislation is designed for the death of large institutions. I don't think so, and that is not the intention. The original bill, yes, in 1983 when I started it. As you remembered, we zeroed out institutions, and then we went up and gave, I believe, it was 20 percent to institutions. Now this gives institutions what they are at now, with a freeze except above 6 percent inflation, and they get that.

But I think we have got to realize that of the 100 percent population current in institutions, some are qualified to leave. I mean you would admit that, wouldn't you?

Mr. KLEPNER. I have.

Senator CHAFEE. Yes, you have.

I don't know what percentage. Even taking the toughest anticommunity approach, if you would, or pro-institution approach, let's say maybe 50 percent can do better in a local setting.

If they move out, that means that presumably the costs of operating that institution are reduced somewhat, so that the available money for the institutions has not declined; it has increased per capita. Isn't that true?

Mr. KLEPNER. Not necessarily. The reason I say not necessarily is that the fixed costs of institutions, hospitals and other types of institutions, remain the same no matter how many patients you may have. So you still need the same physical plant, you still need the same equipment. The difference is that you have fewer people using it and therefore less resources coming in to support it.

Once again, Senator, our problem with the bill is that while you do not immediately kill large institutions, over a period of time the thrust would be exactly the same. If a state is faced with a freeze on Medicaid funding for institutions, while there is no freeze on Medicaid funding for community-based services, you know as well as I do where that money will go, and it will not go into the institutions.

Now, the institutions need funds to keep up to date, to keep physical plant the way it should be maintained, to have adequate salaries for staff, to retain qualified staff as well. Without that money coming in, those institutions won't exist.

Senator CHAFEE. I appreciate that. But we also have to realize, Mr. Klepner, that this isn't a facility freeze. It is a statewide freeze, so that presumably if you have got five institutions in your state, one can be closed—if the population is reduced, one of the five can be closed and thus the amount of money available for the remaining four is actually increased.

But the counter to the argument that with a freeze there will be a thrust toward money for the community, is the reverse; which is, absent that, because of human nature, because of the political process, the money keeps going into the institutions from the state government and not into the community-based facility. That is a fact.

It is much easier for a governor to respond to putting more money into an institution, responding to the institutional employees' requests for pay raises, for upgrading of the institution, better fire escapes, better painting, sprinkler systems, whatever it might be. And that is what happens. The money goes into the institutions and not into the community-based care.

So, absent this legislation, we are not going to see the continuum of care that every single witness says he is for.

Mr. **Klepner**. And with this legislation, Senator, you are not going to see the continuum of care either. The legislation goes way too far in the direction of community-based services. It may sound simple to say if there are five institutions, then what we can do is close one and keep four in existence. But I have seen hospitals close, I have seen institutions close, and those are painful decisions because there are patients there that are going to have to be transferred, and there are patients that may be taken further away from their families, causing that family a great deal of harm in the process.

So it is not simply a matter of closing an institution. There are many human concerns for the patients and their families, as well as the workers, that need to be addressed.

Senator **Chafee**. We recognize that. We have got a fundamental difference here, though.

I don't see, under your proposal and Mr. O'Donnell's and others, that want to keep everything just the way it is as far as the institution goes, how we are ever going to get any thrust toward the community-based facility, community care.

So there we are. You know, they asked the old Baptist preacher: Do you believe in infant baptism? He says, "Believe in it? I've seen it." And I have seen these severely retarded and handicapped youngsters and individuals move into the community setting. I have seen it in my own State. I mean those that no one could say could exist outside of an institution, and there they are, not only existing, but doing better.

And I believe in the testimony that we have had here, that in a smaller setting, as the prior witness testified, Mrs. Jordan, about her daughter in a smaller setting, I just firmly believe these individuals do better.

Senator Heinz from Pennsylvania.

Senator **Heinz**. Mr. Chairman, it has been a long time since I have been able to call you that.

Senator **Chafee**. Well, I like it.

Senator **Heinz**. Mr. Chairman, I want to commend you and Senator Mitchell, the other Chairman, for calling this hearing on S. 1673. I have a prepared statement I would like to put in as part of the record if I may have unanimous consent from the Chair.

Senator **Chafee**. Definitely.

Senator **Heinz**. There is no question but that there are some major changes taking place in the way we look at and treat those who have been institutionalized or have previously been institutionalized.

Maybe this has been touched on, and if it has please tell me. One of the major experiments took place involuntarily in Pennsylvania, my home State, with the court-mandated closing, over a period of years, of Pennhurst.

Mr. Klepner, or Mr. Mattson for that matter, what is there that we can learn from the closing of Pennhurst, both pro and con regarding Senator Chafee's bill?

Mr. KLEPNER. If I may, Senator, Mr. Devereaux has been with AFSCME longer than I have, and he can respond to your question.

Mr. DEVEREAUX. Senator Heinz, I think one of the principal things we could learn from the Pennhurst situation is there are a number of recent lawsuits that have been instigated against some of the community providers for inadequate care. That is a situation that is repeated across the country.

Senator HEINZ. For the record, how many?

Mr. DEVEREAUX. The principal suits are in the City of Philadelphia. I am not sure how many suits. There are a number of them, though.

At the same time, one of the principal right to treatment suits is the Nicholas Romeo case. When Mr. Romeo moved from Pennhurst into the community, our union organized a private sector facility and we found there were just horrible conditions there and it was just very easy to organize the employees because they wanted better working conditions. Mr. Romeo had moved from an institution into a private sector facility that provided inadequate care.

I think that is another example of the cons that you find when you don't have a state operated continuum of care.

Senator HEINZ. Is there any general evidence one way or another that suggests that the court-ordered deinstitutionalization of the patients at Pennhurst was either a mistake and unsatisfactory for most of the people who were there, or that it was, on balance, successful and that they and their loved ones were satisfied?

Is there any evidence one way or the other on that?

Mr. DEVEREAUX. As I have implied, I think the evidence is mixed. I think for some people it was successful; for others it has been very unsuccessful.

Senator HEINZ. But did anyone ever study it carefully?

Mr. DEVEREAUX. I think Valerie Bradley and some of the previous witnesses have looked into that situation.

Senator HEINZ. You are referring to the fact that there was a longitudinal study by Temple University?

Mr. DEVEREAUX. That is correct.

Senator HEINZ. That study is very specific in its findings.

Do you agree or disagree with what they found?

Mr. DEVEREAUX. I am familiar with some of the results, not of the latest study in that series.

Senator HEINZ. Mr. Mattson, do you have any comment on this?

Mr. MATTSON. None specifically, but I think we can talk about lawsuits that have been filed for individuals who have been put in the community from that situation. But I think we also then have to look historically at where some of the lawsuits initially started.

I can think of my own State of Iowa in which there are two pending class action suits against all six mental health institutes and the two hospital schools. We can probably sit here and bandy back and forth, are there more lawsuits against the public institutions or are there more lawsuits against the private? And I think that would be somewhat futile.

Again, I think we have to ask in the end, what is the Medicaid bill for? It is not for the public sector and it is not for the private provider. It is not for the union. It is not for non-union. It is not for parents. It is not to fund bricks and mortar. It is to provide ways of serving people with disabilities in the most appropriate and least costly methods.

We oftentimes think of institutions as relating to certain buildings, whether they be large or small in size. I want to relate briefly a comment of one of the state officials in my own State made just a few months ago. He indicated that the State is the provider, the regulator, and the funder of the institutions, and that he is not about to give up any of those powers.

To me, that is probably one of the worst forms of institutionalization, because that becomes ownership. And I think any time that we start thinking that we own our clients or our patients, we have really gone into, I think, a very poor situation.

The focus of this bill, as well as all of our efforts, should be upon the client, not on what buildings we have—and I have a large investment in the facilities, but that will never dictate nor drive the services that I provide to the people that I am to be serving.

Mr. **Klepner**. Senator, the Public Interest Law Center of Pennsylvania has recently filed a suit on behalf of the Association for Retarded Citizens of Pennsylvania because of abuses and mistreatment of Pinehurst residents now living in the group homes in Philadelphia County.

In the 200 homes that were monitored and that served as the basis of this suit, out of a population of 500 homes which should have been monitored but were not, the following information was found. Fifty-seven percent had out-of-date programs. Eighty-three percent lacked services. Forty-five percent had no programs for taking residents out into the community. Sixty-eight percent of the homes did not provide adequate therapy. Thirty-eight percent of the homes had rapid staff turnover. Thirty-one percent of the homes did not have adequate staffing, and 27 percent of the homes had medical errors in the administration of medication to the residents.

This information, Senator, is on file as part of a motion accompanying this lawsuit.

Senator **Heinz**. Those are allegations in the lawsuit, or are they findings based on the Temple University study? What are they?

Mr. **Klepner**. It is not part of the Temple University Study. It is findings of a special management unit of the state that was asked to monitor 500 group homes and, instead of monitoring 500, monitored 200. And this was information from the study by that group.

Senator **Heinz**. Were the 200 randomly selected?

Mr. **Klepner**. I don't know the answer to that.

Senator **Heinz**. All right. My time has expired.

Thank you all very much.

Thank you, Senator Chafee.

Senator **Chafee**. Thank you, Senator Heinz.

I am going to ask one more question of Mr. Mattson.

First of all, on page 5, you talk about freedom of choice, particularly as regards the case manager selection system. I am not sure I understand the point you are making there, Mr. Mattson.

Mr. MATTSON. One of the concerns we have is that the case management system be independent enough that it can focus on the client. As I mentioned a moment ago, ownership can be an institution without walls; and if we have a state that provides the service, the funding, the regulating and then also throws on case management, they own that person.

And if the focus of this bill is to be on what is in the best interest of the person with a disability, then I think we need to look at developing a case management system that truly can serve that purpose and independent of other conflicts of interest.

Senator CHAFEE. We will look some more into that.

Now, I understand that the private facilities have concerns that under a freeze the states will fund public rather than private institutions. Is there any way we should address that that you can recommend?

Mr. MATTSON. Again, we see that as a possibility, that if there does get to be a financial crunch and states choose not to place individuals from state institutions into the communities, it could increase the state funding dollars that go into those institutions, thereby decreasing what may go into the communities.

Again, I think that we have addressed some of that in the latter part of our testimony in terms of assisting in getting the private sector, as far as their facilities, that we can do some buyouts, some tax credits. I think that we have addressed that a little bit later in that, unless you have specific questions on one of the pages, Senator.

Senator CHAFEE. I did have a question. I think your point about transitional funding on page 8 interests me, and I think I understand that.

Mr. MATTSON. Again, in all due respect to what you just said, whether I take a five-bedroom home that I have or 10, if one of those individuals leave, I have not reduced my cost by one-tenth or one-fifth, and the same is true with larger facilities.

So I think we are saying within the transitional costs, in order to allow for an incentive to develop, we are going to perhaps even sometimes have an increased cost during that transition point, because again it costs no more to have four people in my home as opposed to five, or eight versus 10. The same within the institutions.

So plan for that transition, but at the same time I think there can be some time limits. Again, as I look at my own state institution, I think that as long as we pick one or two or three people out of one area, it will continue to increase the per diem rate because their overall maintenance costs will not reduce. Therefore, if that is going to occur on any major issue, you are going to have to take a look at, on a planned basis, of how many individuals will it take to either reduce or close a building, or transfer staff, or whatever.

We are just saying that in that transition period, look at some of the extra costs that will occur.

Senator CHAFEE. Yes.

Well, I think Mr. Klepner is exactly right when he says in a large institution you decrease the number of residents you don't decrease the cost substantially. You have got a fire department, or a sewage plant, or a hospital, all that, and the costs just don't come down per capita. Indeed, they go up per capita as the population is reduced.

I want to thank both of you gentlemen very much for appearing, and we appreciate it.

The next panel will consist of Mr. Floyd Sorg, and if everybody would come forward, Mrs. Alice Demichelis, Mr. Gilpin, Miss Ward, Ms. Carney, and Mrs. Crawford. So we will go right down in this order.

Mr. Sorg, why don't you go ahead? Won't you proceed, please?

STATEMENT OF FLOYD SORG, BOARD MEMBER, UNITED CEREBRAL PALSY OF PITTSBURGH, AND PARENT OF A SON WITH CEREBRAL PALSY, ELIZABETH, PA

Mr. SORG. My name is Floyd Sorg. My wife and I and my son live in a home in Elizabeth, Pennsylvania outside of Pittsburgh. I am speaking today on behalf of my family, United Cerebral Palsy of Greater Pittsburgh, UCP of Pennsylvania, and United Cerebral Palsy Associations, Inc. and the 700,000 children and adults in this country with cerebral palsy.

Our son Robert was born 20 years ago in December 1967. At the age of six months, the doctors at Children's Hospital told us that Rob had brain damage which caused cerebral palsy, seizures, and mental retardation. They told us he would never be able to do anything and urged us to place him in an institution and forget about him.

We could not and would not do that then, and we do not want to do that to him now. However, if you do not pass the Medicaid Home and Community Quality Services Act of 1987, we may have no choice but to move Rob to a nursing home for old people or a state institution because that is where most of the Medicaid dollars go now.

By the time we learned about UCP in Pittsburgh, Rob was 2-1/2 years old and rolled up in a ball because he had received no therapy. Thank God for UCP. He was enrolled in developmental class to which my wife transported him for a year and a half, 10 miles one way each day.

He entered school in 1972 and in 1976 began getting the benefits of the special education law the Congress passed in 1975, the Education for All Handicapped Children Act. This law allowed Rob to go to school, to learn all that he can, and has allowed us to have new hopes and dreams for his future adult life in the community as part of society.

He has one more year of school and will finish in June of 1989. This young man, who the doctors said wouldn't do anything, can feed himself, respond to our words and is now doing some assembly line work in his vocational program, even though he cannot walk, talk, or toilet himself. Last year he got a wonderful new teacher who purchased an electronic communication device for the schoolroom and Rob is learning how to use it very quickly, but it cost

$3,000 and he only gets to use this one at school. We cannot afford one for him to use at home. Rob likes football and loud music like most young kids his age.

I am a proud man and we haven't asked for or received much from government assistance for Rob other than his rightful education and his S.S.I. checks, but we have had some serious financial problems. In 1984, I was laid off after years of work at U.S. Steel. I have not had a steady job since then. My wife has opened a ceramics shop which is open five days a week from 10 to 3 while Rob attends school.

The small amount of help from the county base service unit of the Department of Mental Retardation amounts to $500 a year for respite care. We pay $150 for two weeks of summer camp, which leaves $350 for respite. At $4 an hour for someone who can lift Rob and meet his needs, that means 90 hours a year, or less than two hours a week.

Senator Chafee. Mr. Sorg, your time is running out, and my question here will not be on your time, but I have been stern on the others. This is excellent testimony, but I will have to cut you off. If you want to proceed up to where your recommendations are, that would be helpful to make sure you fall within the time.

I have read this over, and so I am familiar with it, and it is a terrific presentation, but if we can get to your recommendations. Now I have used up 30 seconds of your time so we will add that on the end.

Mr. Sorg. I don't claim to understand a lot of this legislation and funding, but I do know it doesn't make sense for us to have worked so hard for Rob to live at home and grow up with his family and friends in the community, to spend taxpayers' dollars for him to go to school and learn how to live and work to his potential, if he is then forced to sit at home or go to an institution. He will absolutely disintegrate if he doesn't have the love and support and ongoing stimulation in his life.

United Cerebral Palsy has specific recommendations about the technical aspects of the bill and those are included in the testimony. I know what Rob needs and what other young people like Rob need—a home with other young people in the community with the right kinds of care and support; specialized services, so that he can work at a job he can do; with adaptive equipment like his own communication device; and modifications to the bathroom; respite care for us as long as Rob lives at home, with a minimum of 250 hours a year and a payment rate that will guarantee qualified, responsible people.

This legislation will assure that Rob and our family will have these specialized and individualized services that we need, when we need them.

We have spent 20 years helping Rob, and the mental, physical, and financial burden has been great to us. If you don't help him now with this legislation, he will just sit and become inactive, and so will many more who are like him.

I invite any one of you to come and help take care of Rob for a few days and you will see our problems.

Senator Chafee. You have got 30 seconds more, so you can keep going.

Mr. SORG. That is it.

Senator HEINZ. Could I take 30 seconds just to commend Mr. Sorg for being here? I know he comes down from my home town in Pittsburgh. I am sorry I wasn't here to welcome you when you first came up, but I have read your entire testimony and Senator Chafee will ensure that it is all part of the record.

Senator CHAFEE. Thank you very much, Mr. Sorg. That was extremely interesting and we appreciate your coming.

[The prepared statement of Floyd Sorg appears in the appendix.]

Senator CHAFEE. Mrs. Demichelis.

STATEMENT OF ALICE DEMICHELIS, BOARD MEMBER, NATIONAL HEAD INJURY FOUNDATION, AND PARENT OF A HEAD INJURED SURVIVOR, RESTON, VA

Mrs. DEMICHELIS. Before I begin, I would like to tell you that it was at five o'clock yesterday afternoon that the White House called and said that James Brady could not appear here today. He is starting a new program. I did want him here. He is our honorary spokesperson.

My name is Alice Demichelis. I am a Member of the Board of Directors of the National Head Injury Foundation, a mother of a son who sustained a head injury in 1980, and a full-time volunteer for NHIF as their legislative liaison. Our family resides in Reston, Virginia.

I want to take this opportunity to thank the Committee for inviting me to testify on behalf of the National Head Injury Foundation and myself regarding the importance of the Medicaid Home and Community Quality Services Act.

The National Head Injury Foundation was cofounded in 1980 by Marilyn Price Spivack and Dr. Spivack in Framingham, Massachusetts. We have 18,000 members, 31 state associations, seven affiliate chapters, 350 support groups nationally. We are a nonprofit agency supported by membership due, fundraisers, and contributions and grants.

Our membership is composed of families, friends, medical, social service professionals, and survivors concerned with the well-being of persons with a head injury. Until the establishment of NHIF in 1980, no single existing federal, state or private agency concerned itself exclusively with the unique problems faced by the survivors of head injury and their families. Until NHIF, this lost population was silently and shamefully closeted away and inappropriately placed in psychiatric institutions, schools for people with mental retardation, or nursing homes.

Today, the NHIF proudly serves as the only advocacy organization working to improve the quality of life for those persons confronted by the silent epidemic. The number of deaths each year resulting from trauma of the head is estimated at over 140,000. The estimated prevalence of head injuries in the U.S. is 1.0 million to 1,800,000.

Even more staggering is the fact that 50,000 to 70,000 people a year who survive with a serious head injury are left with intellectual impairment of such a degree as to preclude their return to a normal life. These figures clearly reflect a problem of epidemic proportions.

The Medicaid Home and Quality Services Act is legislation that will help survivors of head injury and their families. With this bill, there is hope for the future. The Medicaid Home and Community Quality Services Act for the first time would make available the community-based services essential to address the needs of those individuals who have suffered a traumatic brain injury.

The availability of individualized community-based services would eliminate current Medicaid practices which have resulted in the inappropriate placement for survivors of head injury in nursing homes or who, by default of services, have been left at home to the care of their loving but inadequately prepared parents or spouse.

States currently spend approximately $2.6 billion for community-based services, which is not matched by federal funds. Under this legislation, 75 percent of those funds would be matchable. The Health Care Financing Administration estimates for fiscal year 1989 show that 200,000 individuals would be eligible for community-based services under current law.

Under the proposed Medicaid Home and Community Quality Services Act, HCFA estimates that 1.4 million individuals, an increase of 500 percent, would be eligible for community-based services in fiscal 1989.

Opponents charge that Senator Chafee's proposal would increase the cost of providing Medicaid through this expansion. However, the cost of traumatic brain injury is presently beyond the means of most Americans.

To further stress the importance of this bill, I would like to add a personal note. When my son Robert was injured in 1980, there were no services for survivors of head injury. Our family became the untrained case managers, psychologists, psychiatrists, and social directors. In reality, we became his only friends.

For the first time in our lives, we were rendered helpless and impotent, at the mercy of the medical profession, employers, the insurance industry, who knew as little about appropriate treatment and rehabilitation of head trauma as we did.

Our federal and state governments and agencies were unable to provide guidance or services due to their own lack of knowledge of this disability. While the situation has improved over the last seven years due to the efforts of the NHIF and it supporters, there is still a great deal more to be accomplished. Passage of this legislation would be part of these positive efforts.

The majority of our survivors, regardless of age, live at home and desperately need community services. Throughout my written testimony, the underscoring theme is that our son was discharged home, to untrained parents and no community services.

This story is not unique among our survivors or their families. If we had had the advantages of the kinds of services outlined in this bill when our son was injured, he would be working today. There are many other survivors of traumatic brain injury who have more severe physical disabilities than our son, and many of them are lying in nursing homes. Many could be more productive members of their families and society with the availability of home and community-based services.

One specific feature of this bill is of extreme importance to survivors of head injury and their families. That provision would increase the age of onset by one year each year after the age of 22. Although many people are head-injured before the age of 22 and would benefit immediately, there are many others that become head-injured after the age of 22.

Few states use Medicaid monies for other than institutionalization.

Senator CHAFEE. Mrs. Demichelis, in fairness I have to cut you off. I have cut others off, and so we will have to draw the line there. I appreciate your testimony and thank you for coming.

Mrs. DEMICHELIS. I just wanted you to know that we support this.

Senator CHAFEE. I got the message.

[The prepared statement of Alice Demichelis appears in the appendix.]

Senator CHAFEE. Mr. Gilpin.

STATEMENT OF R. WAYNE GILPIN, PRESIDENT, AUTISM SOCIETY OF AMERICA, DALLAS, TX

Mr. GILPIN. First of all, I have something in my hand here that I would like you to read, if you can read it from there. It says, "Try to imagine your child is five and has autism."

For me and my son's mother and half a million, over that number, of people living in this country, we did not have to be doing that. We did not have to be trying to guess what it was like to have a child with autism. For us, it was terribly real and a tremendous challenge.

Mr. Chairman, Members, it is an honor to be testifying for S. 1673. As President of the Autism Society and as the parent of Alex, I want to thank you and Senator Chafee for the great step forward this Act will be taking.

First, I would like to note that our group has passed a resolution backing S. 1673 and making its passage our number one priority for this year. We see this bill as the natural step following P.L. 94–142, picking up where the Education for All Handicapped Children Act stopped, at the age of 21.

We see this doing for adults what 94–142 did for all of our children. We are a parent-based group representing 300,000 American citizens who have autism, many of whom are now adults. We, parents, siblings, relatives, and friends, of persons with autism have shouldered the tremendous burden of caring for our very special children with love and with great, great sacrifice. But we can't do it alone. Government understanding and help is absolutely crucial.

We hope that Congress is now ready to take this great step forward with this bill, an honest recognition that people with autism can be helpful members of our society if they are included and not excluded in the mainstream and given an opportunity to be using those talents that they do have.

What we have found is that persons with autism greatly improve when they are daily exposed to the regular community. Therefore, for people with autism, our very best classroom is to be out working with regular folks. This historical lack of programs has had the effect as recently as 10 years ago, of 95 percent of all adults with autism ending up in large institutions.

Although this factor has changed somewhat since then, families still face little real choice between putting their adult offspring in an institution with uncertain aid, or keeping them at home with few or no services.

When a child with autism is born into any family, not only is that child handicapped, but the whole family is. Parents face loss of work; marriages are placed under tremendous stress; and as parents pass away, brothers and sisters stop being brothers and sisters, and they become guardians.

This bill would aid those people in meeting their loving inherited responsibility.

In conclusion, just let me say that we are very much for this bill and will do whatever we actually can to be helping you. I want to thank you and your staff for all the work that has been done on it.

Thank you very much.

Senator **Chafee**. Thank you very much, Mr. Gilpin.

Ms. Nancy Ward.

STATEMENT OF NANCY A. WARD, TREASURER, PEOPLE FIRST OF NEBRASKA, INC., LINCOLN, NE

Ms. **Ward**. Senator Chafee, my name is Nancy Ward. I live in Lincoln, Nebraska and am representing People First of Nebraska.

People First of Nebraska is a self-advocacy organization. Self-advocacy teaches people like me who have a disability to speak out for ourselves, after having people speak out for us. It also teaches us about our rights and responsibilities.

People First has 400 members across Nebraska. As the name implies, we want to be seen as people first, our disabilities second. I am on the Board of Directors and Treasurer of People First. People First has been in Nebraska for 10 years.

One of the rights we have as citizens is to tell the government how we feel about issues that concern us. People First has very strong feelings about S. 1673 because most of our members have lived in institutions for a long time. So we understand what it is like to live in hell.

The difference between living in an institution and the community is like night and day. People are treated as people and not numbers. In the old part of the institution cemetery, graves are marked with a person's number instead of their name.

One of my friends now does things for herself. Example: She learned how to feed herself and decide what she wants to eat, and how to get dressed. These are some of the things that people said they liked about getting out of that place. These are basic rights that we have as citizens and that people take for granted.

We can understand why parents would want to put us in institutions when that or keeping us at home was their only choice, and how hard a decision that would be to make. We also can understand why it would be hard to go through all that pain again by letting us move into the community.

What we don't understand is why society can't see beyond the brick and mortar and see us for what we are: people just like them.

With all the different programs and community access people have in today's society, why is society so afraid to give us the chance to prove ourselves? S. 1673 would give us the money we need to prove ourselves. We would be able to show our communities that we can learn how to live in our own homes and get jobs. We can go to school, do things with our friends, go to the store to buy groceries, and attend the church we want.

In closing, the most important things S. 1673 will do is allow other people who live in institutions to learn what it is like to be given the chance to see themselves as a person, what dignity of risk is, making your own decisions, and doing what you want. If all the above is done, then we will have been able to show society that we are more alike than we are different.

I urge you to support S. 1673.

Senator **Chafee**. Thank you very much, Miss Ward, for that excellent testimony. We appreciate your coming here from Nebraska very much.

Ms. **Carney**.

STATEMENT OF IRENE CARNEY, SPECIAL EDUCATION ADMINISTRATOR, VIRGINIA INSTITUTE OF DEVELOPMENTAL DISABILITIES, RICHMOND, VA

Ms. **Carney**. Mr. Chairman, I appreciate the opportunity to appear this morning, as have the other commenters. I am here in three capacities: as a special education professional, as a member of the Association for Persons with Severe Handicaps, and as the sister of a young woman who died in an institution at the age of 32, even as my family and I tried desperately to move her into a community alternative.

On behalf of TASH I wish to thank you for holding these hearings, and especially to thank you for your longstanding commitment to the redirection of federal funding for the long-term care of individuals with disabilities.

We are an organization of almost 7,000 parents and professionals who advocate for community integration of individuals with severe and profound retardation. Our members believe that communities are for all people and that individuals with even the most challenging disabilities can and should live in their own community.

S. 1673 would afford a clear option for such community living to a number of people for the first time, and we support this effort.

I must say, however, and I know that you know, our support is not without reservation. When you first introduced the amendments, the legislation mandated transfer of all long-term care Medicaid funding from institutional to community services within 10 years. We enthusiastically supported that movement toward community living.

Organizationally, we have struggled with the legislation since that time for two major reasons. First, we feel that S. 1673 has compromised the total transfer of funding from institutional services. People with the most severe disabilities are in the greatest jeopardy of being the residual population, and TASH has grave concern with this fact.

We also have serious concerns with the provisions that allow as many as 15 people to live together under this bill as a qualified community living facility.

In spite of our concerns, we believe this legislation to be a strong first step. I would like to highlight for you the provisions which we believe are especially important. They include the broad definition of people who are eligible for services. We support the establishment of strong federal standard for quality care and we especially applaud the inclusion of a prohibition for the use of aversive techniques for behavior intervention.

We support as one of the strongest and most important pieces of the legislation, the freeze on current institutional funding. This is the only mechanism that will really begin to provide new options in a number of states. We urge the Subcommittee to hold fast to this provision.

Our support is based on our concern for the people with whom we work and live. My personal support is based on my experience with my sister Peggy, who lost her chance to ever experience life in the community. Peggy was labeled profoundly mentally retarded. You have seen in my written comments, Senator Chafee, some history of our family's experiences of seeking but failing to find community services.

I feel, in response to earlier comments this morning, that I would like to comment, instead of detailing that history, that in our experience her institutionalization was necessary only in the absolute absence of the alternatives for community living and support to our family and our home community.

I would very strongly and without qualification assert that it was neither an appropriate nor a beneficial part of the continuum of services in Peggy's experiences.

Three years ago this week, Peggy died of cardiac arrest in Polk Center, which is the 1980s name for Polk State School and Hospital in Polk, Pennsylvania, two hours from my family home. She died of a heart condition that is now routinely and successfully corrected by surgery. In her case. however, it had gone undetected and then misdiagnosed for too long, such that surgery became unavailable at the time that our family sought private consultation and a correct diagnosis.

A week before Peggy's death, I received a letter from a small ICF/MR to which I had applied for the third time over a 10-year period for her transfer. Her acceptance was denied on the basis of her medical fragility. Peggy had been in Polk since 1960 when our mother had died, and our father found it difficult and impossible to care for her special needs as well as the needs of the other four children in our family.

We tried for 10 years previous to her death to have that placement changed. We were not successful because of the absence of alternatives.

Our trips to Polk are over, but our anguish over the fact that she had to live there and certainly our anguish over the fact that in 1985 she had to die there will never be resolved.

Because of our experience and the other experiences of TASH families, such as Elizabeth and Joe Belmonte here in Virginia and Barbara Cutler, who have also rescued their children from dangerous institutional situations, Cynthia Schleininger whose family was unable to care for her in their family home in California because of the unavailability of resources, we have concern about the continuation of institutional care as part of the continuum services.

Your bill would make possible community living for some individuals who have not had that alternative in the past. Let me make it clear, however, that we do not see the community as having magic solutions. As we move away from institutional care, we must have in place strong federal standards for quality of care.

We urge you to pass this legislation as a first step in that direction.

Senator **Chafee**. Thank you very much. I appreciate that testimony, Ms. Carney.

[The prepared statement of Irene Carney appears in the appendix.]

Senator **Chafee**. Let me just say that there is a vote now and I have to go over and vote and will be back—well, there is not a vote, but there will be. We are meant to vote at noon on the President's veto. I suspect we are going to go right into it.

Let me just say, in your testimony, Ms. Carney, you make various statements about institutions where there have been mistreatment of individuals. I am not going to dwell on that because things go wrong in institutions, and things will go wrong in community placement. So I do want to make it clear that frequently we will hear a litany from those opposed as to how community placement has not worked; there have been failures.

There will be failures. And there are failures in an institution, so I am not going to equate one against the other in fairness. Whenever people are involved, things can go wrong, and in neither setting can we guarantee that everything is going to be perfect as far as the individual is concerned. We have to accept that, and we hope that it won't occur.

Ms. **Carney**. That is the reason for our concern and our support for the quality of care standards in the legislation.

Senator **Chafee**. Now here is the vote, and I will go over and vote. If the panel could remain here, because I will have some questions, and then we will take the testimony of Mrs. Crawford. If you will just wait, I will be back very shortly.

Thank you very much.

[Recess.]

Senator **Chafee**. Now let us proceed to our next witness, if we could have quiet, please.

Mrs. Crawford is our last witness. Mrs. Crawford, we welcome you here.

STATEMENT OF PATRICIA CRAWFORD, CHAIR, GOVERNMENTAL AFFAIRS, OF THE MENTAL RETARDATION ASSOCIATION OF NEBRASKA, LINCOLN, NE

Mrs. **Crawford**. Thank you very much, Senator Chafee, for the opportunity to be here today.

I want to present the reasons which compel our opposition to S. 1673 by members of the Mental Retardation Association of Nebraska.

We are the parents and the families and legal guardians of the most severely disabled Nebraskans, those who reside in institutions.

I am Patricia Kelly Crawford from Lincoln. My son Matthew lived at home with his brothers and sisters until he was 14, and at that time we made the decision to place him at the Beatrice State Developmental Center because it was obvious his needs were not being met, neither in our home nor in the community day program that he was involved in.

I am astonished at what they have been able to do with Matthew, the things that he is able to do for himself now, and his contentment and happiness there is wonderful and I am devoted to the Congress for providing that kind of money at Beatrice State Developmental Center and to the citizens of the State of Nebraska.

Now, about this bill. On the one hand, this bill is very generous, with the intent to provide a vast array of services to a vast number of disabled persons in small facilities, and we certainly applaud and approve this.

But this bill has a dark side. While it gives to so many, it takes away from the most severely disabled Americans, those who need and rely on your help the most and those who have depended on Medicaid support since 1977.

We oppose the bill because it is a Trojan horse which will close large facilities, over 15 beds, for the mentally retarded. And an anti-institution bias pervades the entire bill. S. 1673 caps the Medicaid money received by the state for services for severely disabled individuals. With inflation factored in, the net result will be less money to spend for each person.

The Consumer Price Index is now at 4 percent and economists expect that that 4 percent will prevail until approximately the end of the century. In five years, that would amount to a 19.5 percent reduction in real dollars, and by the year 2000 it would be a 38.8 percent reduction in Medicaid money for services to these individuals.

At the same time, the institution has to comply with a maze of federal rules and standards or the facility will be decertified.

The bill also states that if the CPI rises above 6 percent, payments for persons in large facilities would be increased only to the extent that the CPI exceeded 6 percent. For example, if the CPI rose to 7, the payments to those most severely handicapped Americans would only increase by 1 percent.

There is a second cruel freeze in this bill, the freeze-out of parents and legal guardians from the decision making teams for our children. We now have the right to participate in planning life activities for our children. If you pass this bill, some bureaucrat will make the decision to include us "when appropriate." We are scared and we are outraged.

In a 1980 Touche-Ross study of mental retardation programs in Nebraska, they found that the main cost factor in providing services was the number of staff who train and care for the disabled folks. This is the reason it costs more to care for the most severely disabled mentally handicapped people who typically reside in large facilities which provide comprehensive and intensive services and the reason it costs less to provide services to the mildly and moderately retarded folks who are often able to ride the city bus, maybe even hold a job, and are more able to care for themselves.

This bill will require forced removal of persons from large facilities to small facilities. Don't be gulled into believing that men like Matt will be cheaper to serve if moved from point A to point B because the staff needs will not change.

If you believe that old stereotype that these large facilities are warehouses, you have been misinformed, because the Health Care Finance Administration allows no warehousing. Each individual has a program plan for each and every hour of each and every day. If this bill is passed, in a few years institutions would no longer be able to meet HCFA's rigorous standards, would lose Medicaid certification, and be forced to shut down or depend on less reliable funding sources.

They could even revert back to the snakepits and warehouses of more than 20 years ago. God forbid that that could happen.

There are two other provisions in this Trojan horse to close institutions that we object to. This legislation would also require the states to set forth specific objectives and a projected schedule over the next five years for transferring severely disabled persons residing in larger institutions to "more appropriate residential settings." And, two, the bill restricts admissions to any facility larger than 15 beds. This means that any admission would be temporary until a spot in a small facility could be found.

The large facilities that are operated by the Catholics, the Lutherans, and other charities will be subject to this law, too, only they will have to make up the deficit with donations if they can.

The wording in the bill, "transferring persons residing in larger facilities to more appropriate residential settings" clearly reveals the bias against large institutions which pervades this legislation.

Senator CHAFEE. Mrs. Crawford, your time is up. Why don't you get to your conclusions and recommendations?

Mrs. CRAWFORD. My recommendations, sir, would be to write a new bill which would take out the bias against large institutions, a bill which would give parents a choice, parents and families.

I think you would be pleased with the results of that. I see in Nebraska that the people who choose a large facility for their family member chooses it because that family member needs the comprehensive and intensive care that is only found in a large facility.

It is important that you understand how different those folks are who reside in a large facility.

[The prepared statement of Patricia Crawford appears in the appendix.]

Senator CHAFEE. All right, fine. Thank you.

There is one point that you raised—I think it is on page 3—where you talk about freezing out of the parents and guardians from the decision making teams for our children.

In here, there is a provision where the planning does involve the family, and we wanted that in there. However, if you think that is not strong enough——

Mrs. CRAWFORD. It says "when appropriate."

Well, I am sure that if you are a mouthy parent and they don't like what you are going to say, they are not going to invite you.

You see, at the present time, I am a member of Matt's interdisciplinary team, and there is no way they can keep me out. And I think that is very, very bad, to say "when appropriate." Who decides when appropriate?

Senator **Chafee**. Okay. That is a good point and we certainly will look at that and see if we can make changes in that.

Mrs. **Crawford**. You know, 49 states I think have the waiver now, and there is the provision ICF/MR small. Now I don't know why that isn't used more than it has been.

So Medicaid money is available for community programs. Maybe if some of those legislations were facilitated that it would be more simple for a state to provide those sorts of programs, we could get the show on the road. But you know one thing, too, Senator Chafee, different states are in different stages of deinstitutionalization. Nebraska started a lot longer ago than some of the other states, and we have now a waiting list, I think, of 40 for our institutions.

Senator **Chafee**. All right, fine.

All of this has been helpful and I want to thank every member of the panel here for your testimony, each of you, and for the prior witnesses likewise.

Now, what happens next? Many have said what we can do to be helpful? Now, by helpful, of course, obviously I think those who are in favor of the bill. But for those who oppose the bill, the way to influence legislation, obviously, in the Senate is to make every effort to speak to your senators.

For those supporters—and we did have some enthusiastic supporters and we had some who were less enthusiastic—I would tell them how you feel. Each state has two senators. You might think that they are inaccessible. Well, no, they are not. Senators are all subject to reelection, and so I would first identify yourself as a voting member of their state. That will assist your getting their attention. And I would give them your views, each of you.

Obviously, I hope those who are in favor will be vigorous, but those who aren't in favor are listening to these pearls of wisdom and I suppose will act accordingly.

So that is the way you can influence legislation. Senators are not off in some cloud somewhere. They come to your cities and towns. You can make appointments to see them, and get in there and voice your opinions and your views. So that takes care of that.

If any of you have anything beyond what you submitted and you want to suggest for improvement, amendments that might be improving—we received some from the witnesses today, Mrs. Crawford for example, and others have touched on the parent input—we would be glad to hear those suggestions as well.

Again, I want to thank everybody for making the effort to come, and I appreciate it a great deal.

This concludes the hearing.

[Whereupon, at 12:42 o'clock p.m., the hearing was concluded.]

APPENDIX

Alphabetical List and Material Submitted

Opening Statement of Senator Lloyd Bentsen
Health Subcommittee Hearing on S. 1673
The Medicaid Home and Community Quality Services Act of 1987
March 22, 1988

Mr. Chairman (Senator Mitchell), I want to thank you for holding this hearing today on S. 1673, the Medicaid Home and Community Quality Services Act of 1987. This bill is the product of several years of work by the Senator from Rhode Island (Mr. Chafee) and builds upon several earlier versions of the bill introduced in the 98th and 99th Congresses.

This bill is an important proposal, for it would change the way that the Federal-State Medicaid program provides funding for the care and treatment of the severely disabled, primarily the developmentally disabled -- those with mental retardation or related conditions. The bill would provide expanded Federal funding for home and community-based services for the disabled, and freeze the Federal funding for services provided to the disabled in large institutional settings. This proposed shift in Federal funding priorities is not without controversy.

Although over the last ten years interest in small community-based placement has increased, as of June 30, 1986, over two-thirds (100,000 out of 144,000) of Medicaid-eligible individuals with mental retardation or related conditions who receive treatment in Medicaid approved facilities are receiving services in large institutions. We will have some witnesses who will argue that only these larger facilities are capable of providing all the services required by the most severely disabled. We will hear fears expressed by some that a shift of funding priorities to home and community-based care will leave the most severely disabled in the large institutions without adequate funds to provide quality care.

While it is clear that many young people with developmental disabilities could benefit from home and community services, at the same time, we must be careful of embracing any proposal which could leave former residents of institutions without proper care.

My hope is that a balance can be reached that will encourage States to develop a full range of alternatives so that each developmentally disabled individual can live in the most appropriate environment possible, but we must proceed carefully so that we do not jeopardize the health and safety of individuals whose futures will be profoundly affected by decisions we make here in the Congress.

We also must not lose sight of another problem that continues to plague the nation -- the deficit. While Congress has in recent years expanded the Medicaid program, even in these times of deficit reduction, we do not have unlimited Federal funds available for program expansions. The actuaries of the Health Care Financing Administration have estimated that this bill would cost $1.3 billion in Fiscal Year 1989, and increase over time to $2 billion per year by the year 2000. The Congressional Budget Office disagrees with these projections, but has not yet established an official estimate.

We also must keep in mind that Medicaid requires that the States pay a portion of the costs of the program. If States do not have the funds to expand home and community-based services, we must be careful not to merely encourage deinstitutionalization through reduced Federal payments for institutional care, at a time when some states are not financially capable of providing the replacement home and community-based services that will be necessary.

I look forward to hearing the testimony this morning.

STATEMENT OF SENATOR JOHN HEINZ
COMMITTEE ON FINANCE
MARCH 21, 1988

MR. CHAIRMAN, I WANT TO COMMEND YOU FOR CALLING THIS HEARING ON S. 1673, THE "MEDICAID COMMUNITY QUALITY SERVICES ACT", INTRODUCED BY SENATOR CHAFEE. THIS IS AN IMPORTANT PROPOSAL FOR THE RETARDED, DISABLED, AND THEIR FAMILIES. IT DESERVES CAREFUL CONSIDERATION. TODAY'S HEARING WILL PROVIDE A USEFUL RECORD ON THIS ISSUE, AS WELL AS THE OPPORTUNITY FOR ALL INTERESTED PERSONS TO SHARE THEIR VIEWS AND RECOMMENDATIONS.

THIS LEGISLATION WOULD SIGNAL A FUNDAMENTAL CHANGE IN FEDERAL MEDICAID POLICY FOR THE RETARDED AND DISABLED. IN 1986, OVER 140,000 AMERICANS WITH MENTAL RETARDATION OR RELATED CONDITIONS LIVED IN MEDICAID-FUNDED INTERMEDIATE CARE FACILITIES FOR THE MENTALLY RETARDED. MANY OTHERS LIVE AT HOME WITH THEIR FAMILIES, OR IN SMALL COMMUNITY SETTINGS.

OVER THE YEARS, OUR UNDERSTANDING OF THE NEEDS AND CAPABILITIES OF PEOPLE WITH DISABILITIES HAS PROGRESSED. THE EDUCATION OF THE HANDICAPPED ACT AND SECTION 504 OF THE REHABILITATION ACT WERE MILESTONES IN FEDERAL POLICY ENABLING RETARDED AND HANDICAPPED AMERICAN'S THE OPTION TO PARTICIPATE IN THE MAINSTREAM OF SOCIETY. OUR HEALTH POLICY, HOWEVER, HAS YET TO FULLY ADDRESS THE UNMET NEEDS FOR COMMUNITY CARE. THIS IS TRUE FOR BOTH THE DISABLED AND OLDER AMERICANS. MEDICAID SERVES SOME OF THE LONG TERM CARE NEEDS OF THESE VULNERABLE CITIZENS, BUT NOT ALL.

UNTIL 1981, MEDICAID POLICY FOR THE MENTALLY RETARDED AND DEVELOPMENTALLY DISABLED REIMBURSED ONLY INSTITUTIONAL CARE. WITH THE ADOPTION OF THE 2176 WAIVER PROGRAM IN THE OMNIBUS BUDGET RECONCILATION ACT, SOME FEDERAL SUPPORT FOR COMMUNITY CARE HAS BEEN MADE AVAILABLE. THE PROGRESS HAS BEEN MODEST, FEDERAL SPENDING UNDER THE 2176 WAIVER WAS $145 MILLION IN 1986, WITH TOTAL FEDERAL DOLLARS GOING TO COMMUNITY CARE AMOUNTING TO JUST OVER $800 MILLION. IN THAT SAME YEAR, STATES PAID $2.7 BILLION FOR THIS CARE. FEDERAL SUPPORT HAS TRADITIONALLY BEEN TARGETED TO INSTITUTIONS RANGING IN SIZE FROM SIXTEEN TO OVER 1,000 BEDS. TODAY, WE HAVE AN OPPORTUNITY TO REVIEW THE POTENTIAL BENEFITS AND ANY SHORTCOMINGS OF THIS POLICY.

FOR INSTANCE, I UNDERSTAND THAT OUR WITNESSES WILL DESCRIBE THE DESIRE FOR BOTH INSTITUTIONAL CARE AND COMMUNITY SERVICES TO MEET THE NEEDS OF OUR RETARDED AND DISABLED CITIZENS. AND I WOULD PARTICULARLY LIKE TO WELCOME MR. FLOYD SORG, WHO IS HERE REPRESENTING UNITED CEREBRAL PALSY OF PITTSBURGH, IN MY HOME STATE OF PENNSYLVANIA. I LOOK FORWARD TO HIS TESTIMONY.

THANK YOU, MR. CHAIRMAN.

STATEMENT OF SENATOR WILLIAM ARMSTRONG ON THE MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT OF 1987

MR. ARMSTRONG: Mr. Chairman, I am pleased the Finance Committee is holding this hearing on S. 1673. I am happy to join Senator Chafee in cosponsoring this measure because it strikes me as a truly a historic proposal in the evolution of policy for the developmentally disabled. For the past decade, care for the developmentally disabled has gradually shifted from institutions to community-based settings. This legislation recognizes the importance and soundness of that trend, and seeks to encourage it.

Medicaid is the principle Federal program providing long term care to the retarded, and in my view it is way behind the times. Even though care has steadily shifted to the community, Medicaid pays primarily for institutional care. I think that is an unfortunate bias, and this legislation tries to correct it. I know some believe deeply that institutional care must always exist for those who, regretfully, may never be able to make a go of it on the outside. This bill does not eliminate that option. But I suspect that in the large majority of cases, even the most difficult forms of retardation, community care can work if the proper resources are devoted to it. The ultimate objective of society's treatment of the developmentally disabled should be to help these individuals become able to live a life as normal and happy as possible in the community, and not simply to care for their human needs isolated from the rest of us. Community living and the chance to development friendships is something we all probably take for granted, but it is crucial to the personal development of a retarded citizen.

I think it is fair to say the State of Colorado has been a leader in moving toward community-based care for the retarded. Colorado has made extensive use of the present waiver under Medicaid in developing community alternatives. I can recount for this committee the heart-touching success stories of several Colorado residents who lived in institutions for decades -- in some cases their entire lives -- who were considered completely hopeless, and who literally have been given a new life in community-based settings. In this regard, I want to acknowledge the excellent work of the Colorado Developmental Disabilities Planning Council and the Association of Retarded Citizens of Colorado for their good efforts. They have helped educate me on this issue and done a tremendous service for the cause of the retarded in my home state.

I do not routinely sponsor proposals to expand Federal programs. And I understand the cost of this initiative is a matter of some disagreement. I hope this hearing will shed light on that subject, because cost considerations are not unimportant. I know Senator Chafee is committed to making this proposal as cost-effective as possible. But in the final analysis, this initiative is far more worthy than dozens of other Federal programs I would gladly do away with. Those who will benefit are among the most deserving of our citizens: retarded individuals with minimal resources. The legislation is intended to help them become successful and independent members of their communities, and less dependent on institutions and government aid.

I also understand there is some disagreement about other aspects of this bill. I welcome such differences. This hearing is the beginning of a process in which views are exchanged and, hopefully, a better understanding of the problem and how to solve it achieved. I look forward to learning from the testimony to be presented and I stand ready to work with all interested parties to craft the best possible bill.

TESTIMONY OF SENATOR LOWELL P. WEICKER, JR.
ON S.1673, THE MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT
MARCH 22, 1988

MR. CHAIRMAN AND MEMBERS OF THE COMMITTEE, I APPRECIATE THE OPPORTUNITY TO TESTIFY TODAY AS YOU CONSIDER S. 1673, THE "MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT". THIS LEGISLATION WILL MAKE FAR-REACHING CHANGES IN THE WAY WE FUND MEDICAID SERVICES FOR PEOPLE WITH DISABILITIES. YET THEY WILL NOT BE THE ONLY ONES TO BENEFIT FROM THESE CHANGES: THEIR FAMILIES AND THE COMMUNITIES IN WHICH THEY WILL RESIDE WILL ALL BE THE RICHER FOR THEIR LIBERATION FROM THE CONFINES OF THE INSTITUTION.

DISABILITIES ARE NOT SELECTIVE ABOUT THE FAMILIES THEY TOUCH. WE ARE ALL POTENTIAL CANDIDATES. BUT HOW WE ADDRESS THE NEEDS OF INDIVIDUALS WITH DISABILITIES IS NOT JUST AN ISSUE FOR FAMILIES. IT IS AN ECONOMIC AND HUMANITARIAN ISSUE THAT GOES TO THE VERY ESSENCE OF WHAT WE STAND FOR AS A NATION.

IN HIS COMPREHENSIVE CASEBOOK, THE LEGAL RIGHTS OF HANDICAPPED PERSONS, ROBERT L. BURGDORF, JR. WRITES THAT "THE HISTORY OF SOCIETY'S FORMAL METHODS FOR DEALING WITH HANDICAPPED PEOPLE CAN BE SUMMED UP IN TWO WORDS: SEGREGATION AND INEQUALITY". WHETHER IT WAS THOUGHT NECESSARY TO PROVIDE THEM SPECIAL CARE AND PROTECTION FROM SOCIETY, OR BECAUSE THEY WERE THOUGHT TO BE DANGEROUS TO SOCIETY, THE OVERRIDING ASSUMPTION WAS THAT DISABLED INDIVIDUALS HAD NOTHING TO CONTRIBUTE, COULD NOT SUPPORT THEMSELVES OR CONTROL THEIR LIVES.

IN RECENT DECADES, WE HAVE WITNESSED A WAVE OF ACTIVISM AND ACCOMPLISHMENT BY AND FOR PEOPLE WITH DISABILITIES. THERE HAVE BEEN FORWARD STRIDES ON SO MANY FRONTS--IN EDUCATION, HEALTH CARE, EMPLOYMENT AND CIVIL RIGHTS, TO NAME A FEW. ADVANCES IN EDUCATION

HAVE DEMONSTRATED THAT EVEN SEVERELY DISABLED PEOPLE HAVE A CAPACITY FOR LEARINING; ADVANCES IN TECHNOLOGY HAVE DEMONSTRATED THAT PHYSICAL HANDICAPS CAN BE OVERCOME AND COMPENSATED FOR. LEGAL ADVOCATES HAVE ARGUED THAT HANDICAPPING CONDITIONS ARE NOT A LEGITIMATE EXCUSE FOR DENYING A PERSON HIS OR HER CONSTITUTIONAL RIGHTS, AND THE FEDERAL COURTS HAVE AGREED, ISSUING LANDMARK DECISIONS. AMONG EDUCATORS AND EMPLOYERS AND IN SOCIETY AT LARGE, THERE IS A GREATER UNDERSTANDING THAT STEREOTYPES AND LABELS ARE DEMEANING AND DESTRUCTIVE. YET DISABLED PEOPLE HAVE REPEATEDLY SHATTERED THE LOW EXPECTATIONS BORN OF OUR PREJUDICES AND EMBEDDED IN OUR PUBLIC POLICIES.

TODAY WE CAN BE PROUD THAT MANY OF OUR LAWS, SUCH AS THE EDUCATION OF THE HANDICAPPED ACT, THE REHABILITATION ACT AND THE DEVELOPMENTAL DISABILITIES ACT REFLECT THE CURRENT STATE OF OUR KNOWLEDGE ABOUT THE ABILITIES OF PEOPLE WITH DISABILITIES. RECENT AMENDMENTS TO THESE LAWS ARE ENABLING STATES TO BEGIN SERVING DISABLED INFANTS FROM BIRTH, IN ORDER TO MITIGATE THE EFFECT OF HANDICAPPING CONDITIONS AND MAXIMIZE INDIVIDUAL DEVELOPMENT. THEY ARE CREATING JOB OPPORTUNITIES THROUGH A NEW SUPPORTED EMPLOYMENT PROGRAM SO THAT EVEN PEOPLE WITH THE MOST SEVERE DISABILITIES CAN ENTER THE MAINSTREAM OF COMPETITIVE EMPLOYMENT. EACH OF THESE LAWS RECOGNIZE THAT INDEPENDENCE, PRODUCTIVITY AND INTEGRATION ARE NOT JUST DESIRABLE, BUT REALISTIC GOALS FOR DISABLED AMERICANS.

YET, DESPITE OVER A THREE BILLION DOLLAR COMMITMENT TO CARRYING OUT THESE LAWS, WE ARE STILL SPENDING NEARLY THE SAME AMOUNT OF FEDERAL FUNDS TO SUPPORT AN ANTIQUATED SYSTEM OF SERVICES THROUGH THE "INTERMEDIATE CARE FACILITY FOR THE MENTALLY RETARDED", OR ICF/MR PROGRAM, UNDER MEDICAID.

WHEN CONGRESS CREATED THE ICF/MR PROGRAM 18 YEARS AGO, IT ASSUMED THAT FEDERAL MEDICAID DOLLARS WOULD BE DIRECTLY LINKED WITH QUALITY SERVICES. AT THE SAME TIME, THE PROGRAM WAS

STRUCTURED IN A MANNER THAT IS INSTITUTIONALLY-BIASED, WITH FUNDING GOING PRIMARILY TO LARGE INSTITUTIONS AND FEW DOLLARS DIRECTED TOWARDS KEEPING PEOPLE WITH DISABILITIES IN THEIR HOMES AND COMMUNITIES WITH THE ASSISTANCE THEY NEED.

WE KNOW THAT VERY OFTEN INDIVIDUALS CONFINED TO INSTITUTIONS COULD BE LIVING IN THE COMMUNITY DOING MEANINGFUL WORK AND EXPERIENCING MANY OF THE ROUTINE EVENTS OF DAY-TO-DAY LIFE WHICH YOU AND I TAKE FOR GRANTED. AND WE KNOW THAT DISABLED YOUNG ADULTS, RAISED IN THE MAINSTREAM OF LIFE, WANT TO STAY IN THERE. BUT THE EXISTING MEDICAID SYSTEM INHIBITS AND FRUSTRATES THE DEVELOPMENT OF THE SUPPORT SYSTEM NECESSARY FOR THIS TO HAPPEN. INSTEAD, MEDICAID HAS BEEEN A BARRIER TO INDEPENDENCE, PRODUCTIVITY AND INTEGRATION FOR THOSE DISABLED INDIVIDUALS IT WAS DESIGNED TO HELP. IT IS A PROGRAM THAT IS COSTLY NOT JUST IN DOLLARS SPENT, BUT IN LIVES WASTED.

AS LAWMAKERS, IT IS OUR RESPONSIBILITY TO ENACT LEGISLATION CONSISTENT WITH CONSTITUTIONAL GUARANTEES OF EQUAL RIGHTS. YET THE MEDICAID PROGRAM AS IT RELATES TO THE DISABLED CAN STILL BE SUMMED UP IN THE TWO WORDS "SEGREGATION" AND "INEQUALITY", FOR IT IS BASED ON OUTMODED STEREOTYPES OF PEOPLE WITH DISABILITIES.

S.1673, THE "MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT", INTRODUCED BY SENATOR CHAFEE, MYSELF AND OTHERS LAST SEPTEMBER, APPLIES OUR ENLIGHTENED UNDERSTANDING OF DISABILITY TO THE MEDICAID PROGRAM.

S. 1673 IS GROUNDED IN THE KNOWLEDGE THAT THERE CAN BE ALTERNATIVES TO INSTITUTIONAL CARE--ALTERNATIVES THAT ARE COST-EFFECTIVE FOR OUR NATION, AND THAT WILL PRODUCE A BETTER QUALTIY OF LIFE FOR PEOPLE WITH DISABILITIES. S.1673 IS BASED ON THE BELIEF THAT A VARIETY OF QUALITY, MEDICAID-FUNDED SERVICES FOR PEOPLE WITH DISABILITIES SHOULD BE AVAILABLE IN A WIDE RANGE OF

SETTINGS, AND THAT SERVICE DECISIONS SHOULD BE MADE TO MAXIMIZE INDEPENDENCE, PRODUCTIVITY AND INTEGRATION INTO THE COMMUNITY. FOR THIS TO HAPPEN, THE INSTITUTIONAL BIAS IN THE EXISTING MEDICAID SYSTEM MUST BE REMOVED, AND FUNDING FOR QUALITY COMMUNITY SERVICES AND SUPPORTS MUST BE AVAILABLE.

TO FURTHER THESE GOALS, S.1673 WOULD FREEZE THE LEVEL OF FEDERAL FUNDS GOING TO LARGE INSTITUTIONS, AND REQUIRE THAT EVERY STATE PARTICIPATING IN THE INSTITUTIONAL ASPECT OF THE MEDICAID PROGRAM ALSO DEVELOP AN ARRAY OF QUALITY COMMUNITY SERVICES AND SUPPORTS. IT ALLOWS FOR CHOICE AMONG THE VARIOUS AVAILABLE SERVICES, AND CHOICE AMONG A VARIETY OF LIVING SITUATIONS. MOST OF US TAKE THE CHOICES WE HAVE IN OUR LIVES FOR GRANTED. BUT FOR MANY PEOPLE WITH DISABILITIES AND THEIR FAMILIES THERE HAVE BEEN NO CHOICES--EVEN WHEN THEY COULD RESULT IN LESS COST TO THE FEDERAL GOVERNMENT.

I WANT TO TAKE A FEW MINUTES TO HIGHLIGHT FOR YOU SOME OF THE PROVISIONS IN S.1673 WHICH HAVE BEEN CONTROVERSIAL. I WANT TO DO SO BECAUSE THERE IS SOME MISUNDERSTANDING ABOUT THE GOALS OF THIS IMPORTANT LEGISLATION, AND CONFUSION ABOUT HOW THOSE GOALS WILL BE ACHIEVED.

FIRST, THERE ARE THOSE WHO FEEL THAT THIS IS STRICTLY A "DEINSTITUTIONALIZATION" BILL; THAT FREEZING THE AMOUNT OF FEDERAL FUNDS GOING TO INSTITUTIONS WILL DISCRIMINATE AGAINST THOSE IN INSTITUTIONS BY VIRTUE OF THEIR RESIDENCE, AND DENY THEM ACCESS TO A FULL CONTINUUM OF SERVICES. I WANT TO MAKE IT VERY CLEAR THAT THE PURPOSE OF THIS BILL IS NOT TO CLOSE THE INSTITUTIONS. I HAVE NEVER SUPPORTED THE FORCED SHUTDOWN OF THESE FACILITIES, NOR DO I INTEND TO. BUT DISCRIMINATION DOES EXIST. IT EXISTS FOR THOSE WHO DO NOT WANT TO BE CONFINED IN INSTITUTIONS, AND THOSE WHO WANT TO REMAIN IN THEIR HOMES AND COMMUNITIES. IT IS THESE PEOPLE WHO FACE DISCRIMINATION BECAUSE OF THE INSTITUTIONAL BIAS IN THE EXISTING SYSTEM. S.1673 WILL OFFER CHOICES THAT WILL CREATE, NOT REMOVE, A FULL RANGE OF OPTIONS.

THERE ARE ALSO THOSE WHO FEEL THAT S.1673 WOULD FORCE STATES TO PLACE RESIDENTS IN THE COMMUNITY WITHOUT PROPER SUPPORTS. I DO NOT BELIEVE THIS WILL HAPPEN. I WOULD LIKE TO POINT OUT TO THE COMMITTEE THAT ALL 50 STATES HAVE PURSUED A POLICY OF REDUCING THE NUMBER OF PEOPLE LIVING IN LARGE INSTITUTIONS FOR THE LAST DECADE. S.1673 PROVIDES STRONG INCENTIVES TO CONTINUE THIS POLICY, BY FREEZING THE FEDERAL FUNDS GOING TO THE INSTITUTIONS, AND BY MAKING COMMUNITY SERVICES REIMBURSABLE UNDER MEDICAID.

A CRITICAL COMPONENT TO ENSURING THAT INAPPROPRIATE PLACEMENTS DO NOT OCCUR IS THE ELABORATE SYSTEM OF CHECKS AND BALANCES BUILT IN TO THE QUALITY ASSURANCE SECTION OF THE BILL, WHICH WOULD BE REQUIRED OF STATES FOR APPROVAL OF THEIR STATE MEDICAID PLANS. HAVING COMMUNITY OPTIONS CLEARLY IS OF LITTLE VALUE IF WHAT OCCURS IN THE COMMUNITY IS NOT OF HIGH QUALITY. I KNOW THAT CONDITIONS IN THE COMMUNITY CAN BE EVERY BIT AS ABUSIVE AS THOSE WHICH I FOUND IN SOME LARGE INSTITUTIONS SEVERAL YEARS AGO DURING THE INVESTIGATION BY THE SUBCOMMITTEE ON THE HANDICAPPED. AND I THINK THAT ONE REASON SUCH CONDITIONS EXIST IS BECAUSE OF THE LACK OF QUALITY ASSURANCE AND MONITORING MECHANISMS FOR COMMUNITY PROGRAMS, AND THE LACK OF FEDERAL FUNDS FOR THEIR SUPPORT.

THE QUALITY ASSURANCE PROVISIONS INCLUDED IN S.1673 WERE DESIGNED NOT JUST TO PREVENT ABUSE AND NEGLECT FROM OCCURRING IN THE NEW, MEDICAID-REIMBURSABLE COMMUNITY PROGRAMS, BUT ALSO TO ENSURE THAT THESE COMMUNITY PROGRAMS PROVIDE OPTIONS THAT ARE APPROPRIATE, OPTIONS THAT WILL INCREASE THE QUALITY OF LIFE FOR PEOPLE WITH DISABILITIES AND MAXIMIZE THEIR ABILITY TO BECOME INDEPENDENT, PRODUCTIVE, INTEGRATED MEMBERS OF OUR COMMUNITIES.

SOME OF THESE QUALITY ASSURANCE PROVISIONS HAVE BEEN CALLED INTO QUESTION, SUCH AS THE NEED FOR A CASE MANAGEMENT SYSTEM THAT IS INDEPENDENT OF ANY SERVICE PROVIDER. BUT I WOULD LIKE TO POINT OUT TO THE COMMITTEE THAT ONE OF THE PRIMARY FINDINGS OF THE SUBCOMMITTEE'S INVESTIGATION OF INSTITUTIONS WAS THAT INDEPENDENCE

IS CRITICAL TO PREVENTING ABUSE AND NEGLECT AND ENSURING THAT APPROPRIATE SERVICES ARE PROVIDED. INDEED, I FEEL THAT THE INDEPENDENT CASE MANAGEMENT SYSTEM IS ONE OF THE CORNERSTONES OF THE QUALITY ASSURANCE SECTION OF THE BILL. WHILE THESE QUALITY ASSURANCE PROVISIONS TO WHICH STATES WOULD BE SUBJECTED ARE DETAILED, AND SOME MIGHT ARGUE THAT SUCH DETAIL SHOULD BE SAVED FOR REGULATIONS, I DISAGREE. INSTEAD, I THINK SUCH SPECIFICITY IS CRITICAL IN ORDER TO ENSURE THAT WE DON'T LET FEDERAL FUNDS AGAIN BE USED TO SUBSIDIZE CONDITIONS OF ABUSE AND NEGLECT.

OTHERS ARGUE THAT S.1673 COULD HARM THE MOST SEVERELY DISABLED WHO REQUIRE A GREATER LEVEL OF CARE. HOWEVER, RESEARCH INDICATES THAT IT IS IN FACT THE SEVERELY DISABLED WHO BENEFIT THE MOST WHEN THEY MOVE TO MORE INTEGRATED SETTINGS. I WILL BE HAPPY TO ASK MY STAFF TO MAKE THESE STUDIES AVAILABLE TO YOU, SHOULD YOU DESIRE MORE INFORMATION IN THIS AREA. AND AGAIN I REFER TO THE DETAILED QUALITY ASSURANCE COMPONENTS IN THE BILL WHICH STIPULATE THAT IT IS ONLY WHEN A PROGRAM IS BOTH APPROPRIATE TO THE NEEDS OF THE INDIVIDUAL AND AVAILABLE IN THE COMMUNITY THAT MOVEMENT TO THE COMMUNITY IS CONSIDERED.

SOME SAY THAT S.1673 DOES NOT ADDRESS THE NEED FOR QUALITY IN THE INSTITUTIONS. HOWEVER, THE BILL PROVIDES FOR ADMINISTRATIVE RESPONSIBILITIES TO BE CENTRALIZED IN A NEW BUREAU WITHIN THE DEPARTMENT OF HEALTH AND HUMAN SERVICES IN ORDER TO PROVIDE INFORMED AND COORDINATED LEADERSHIP ON ALL MEDICAID PROGRAMS AFFECTING PEOPLE WITH DISABILITIES, WHETHER IN INSTITUTIONS OR IN THE COMMUNITY. THIS NEW BUREAU WOULD BE STAFFED BY PEOPLE KNOWLEDGEABLE OF DISABILITY ISSUES, AND WOULD HAVE NUMEROUS NEW RESPONSIBILITIES WHICH WOULD IMPROVE THE QUALITY OF INSTITUTIONAL LIFE.

HOWEVER, I WOULD LIKE TO ADD THAT WHILE I DO NOT FAVOR THE FORCED CLOSING OF INSTITUTIONS, AND I AM MOST CERTAINLY CONCERNED ABOUT THE QUALITY OF THEIR PROGRAMS, THE FUTURE FOR PEOPLE WITH

DISABILITIES CANNOT BE ONE OF SEGREGATION FROM THE MAINSTREAM OF LIFE. GIVEN QUALITY CHOICES IN THE COMMUNITY, FEW WOULD CHOOSE THE REGIMENTED, ISOLATED LIFE OF THE INSTITUTION. PEOPLE WITH DISABILITIES HAVE SPOKEN CLEARLY AND ELOQUENTLY ON THIS POINT. THEY WANT CHOICES IN THEIR LIVES: CHOICES TO STAY IN THEIR COMMUNITIES, TO HAVE MEANINGFUL WORK, TO ASSOCIATE WITH NON-DISABLED PEOPLE, AND TO LIVE INDEPENDENTLY AND WITH DIGNITY.

I BELIEVE THAT PEOPLE WITH DISABILITIES IN OUR COUNTRY DESERVE ACCESS TO QUALITY SERVICES THAT ARE LEAST RESTRICTIVE OF THEIR FREEDOM AND MOST EFFECTIVE IN ENSURING EQUALITY OF OPPORTUNITY. I BELIEVE THAT S.1673 PROVIDES THE MECHANISM TO ACCOMPLISH THIS GOAL, AND THIS COMMITTEE HOLDS THE KEY THAT WILL OPEN THE DOOR TO THOSE SERVICES.

I DO NOT MEAN TO IMPLY THAT S.1673 IS PERFECT, OR THAT I ASSUME ITS IMPLEMENTATION WILL BE TROUBLE-FREE. WHILE I BELIEVE THAT THE STATES ARE COMMITTED TO DEVELOPING QUALITY COMMUNITY PROGRAMS, THEIR PROGRESS WILL REQUIRE THE ACTIVE INVOLVEMENT OF FAMILIES, ADVOCATES AND OTHERS TO ENSURE THAT THIS EVOLUTION TAKES PLACE.

FINALLY, I WOULD LIKE TO EXTEND MY SPECIAL THANKS TO SENATOR CHAFEE FOR HIS LEADERSHIP IN DEVELOPING THIS LEGISLATION. HE HAS BEEN A TIRELESS AND UNWAVERING ADVOCATE FOR PEOPLE WITH DISABILITIES IN THEIR ATTEMPTS TO GAIN ACCESS TO THE COMMUNITY, AND TO TAKE PART IN THE THINGS THAT MOST OF US ENJOY IN THIS NATION. I COMMEND HIM, AND THE OTHER MEMBERS OF THIS COMMITTEE, FOR RECOGNIZING THAT THE TIME HAS COME TO MAKE EQUALITY AND INTEGRATION--NOT SEGREGATION AND INEQUALITY--A PROMISE OF THE MEDICAID PROGRAM. WITH THIS BILL, WE HAVE THE OPPORTUNITY TO ENSURE THAT NO DISABLED PERSON IS FORCED TO ABANDON THEIR HOPES FOR A BRIGHT TOMORROW BECAUSE THERE ARE NO ALTERNATIVES.

THANK YOU.

K. Charlie Lakin

Testimony to the U.S. Senate Subcommittee on Health, Committee on Finance

at hearings on
S.1673, the Medicaid Home and Community Quality Services Act

March, 22, 1988

My name is Charlie Lakin. I am Director of Research of the Minnesota University Affiliated Program at the University of Minnesota. Over the past 10 years my colleagues and I have been involved in gathering and maintaining statistics on long-term care and alternative services for persons with developmental disabilities. Title XIX, and most notably the Intermediate Care Facility for the Mentally Retarded (ICF-MR) program has been an unavoidable focus of attention over those years. The ICF-MR program encompasses almost three-fourths of the funds and about 57% of the residents in long-term care settings for persons with developmental disabilities. The ICF-MR and Medicaid waiver payments under Title XIX represent about 57% of all federal residential, educational, habilitation, medical and other forms of non-cash assistance to persons with developmental disabilities (Braddock, et al., 1987). The ICF-MR program is, in short, the primary means by which the federal government assists with services for persons with developmental disabilities in the U.S.

It is said, fairly, I believe, that the policy is in the implementation. It is not what policy says, but what policy does that matters. It seems clear to me that when one looks with any sensitivity or sensibility at current federal policy, he/she will recognize that time for very significant change has arrived. Over the past year I've had the privilege to participate as a consultant in a very detailed and thoughtful analysis of federal policy on services for persons with developmental disabilities involving several key agencies within the Department of Health and Human Services. The report of that "Working Group" has not yet been cleared, so I will not discuss its recommendations. However, I would like to quote one paragraph from its introduction regarding current ICF-MR policy:

> A number of critics have questioned whether public policies, particularly Federal financing policies, have kept pace with the dramatic changes that have occurred in the field. The conclusion of this report is that the critics are largely right. The most significant Federal program specifically designed to finance services, the Intermediate Care Facilities for the Mentally Retarded

(ICF/MR) program, is institution-based; to be eligible for services, individuals must be placed outside their homes and be in need of "active treatment" and 24-hour supervision. Three quarters of the persons served by this program are in large (average size 155 beds), costly state mental retardation facilities which are segregated from the rest of society. These institutions frequently are unable to provide opportunities for independence, productivity, and integration into the community, the Federal policy goals expressed in the Developmental Disabilities Amendments of 1984, and reaffirmed in 1987 amendments.

Professed Goals of Congress and the Effects of Present Policy

Federal policy in this area is clearly drastically out of synchrony with the ideals that Congress has elsewhere espoused and the general trends within the evolving systems serving persons with developmental disabilities. Congress noted in its findings of 1987 Developmental Disabilities Act, that "it is in the national interest to offer persons with developmental disabilities the opportunity, to the maximum extent feasible, ... to live in typical homes and communities where they can exercise their full rights and responsibilities as citizens." The ICF-MR program does not reflect a productive effort to advance this particular national interest. Let me cite just a few statistics that demonstrate this observation.

- Although the ICF-MR program accounts for over one-third of all federal expenditures for persons with developmental disabilities (Braddock, et al., 1987), only 4%-8% of the persons with developmental disabilities benefit from the program. The 144,000 people participating in the program in 1986 were doing so at an average annual cost of $35,000. In contrast, the 23,000 Medicaid waiver beneficiaries in 1986 had an average annual cost of $9,500.

- Despite very substantial shifts away from public institutional placement of persons with developmental disabilities, the ICF-MR program remains primarily involved in support of public institutions. In 1977, there were over 151,000 people in state institutions. In 1987 there were about 96,000. In 1977 over 60% of the persons with developmental disabilities in residential settings were in state institutions. By 1986 the number had decreased to under 40%. These changes are poorly reflected in the ICF-MR program which in 1986 reimbursed the care of almost the same number of persons in state institutions (91,000) as it did in 1977 (92,500). In 1986, 75% of all ICF-MR reimbursements went to state institutions and 63.3% of all ICF-MR beneficiaries lived in large public institutions.

- There has been a dramatic increase in federal participation in supporting large private residential facility care between 1977 and 1986. Although nationwide during this period there was a decrease in the total number of people in large private institutions from about 51,600 to 46,700, the number of people whose care was cost shared under the ICF-MR program increased from 12,000 to 32,000.

- There was a substantial increase in ICF-MR services in relatively small community settings (15 or fewer residents) between 1977 and 1986. The total number of these residents increased from 1,725 to 20,900. Still, the low level of involvement of the ICF-MR program in supporting community-based services is impressive. While nationally in 1986 41% of the residents of long-term care settings for persons with developmental disabilities were in facilities of 15 and fewer residents, only 14.5% of ICF-MR residents were in small facilities. This contrasts dramatically with the 83% of persons in large public and private institutions who were in programs with federal ICF-MR cost sharing.

- Because states are ambivalent toward the benefits of ICF-MR program in funding community services, they vary dramatically in their levels of participation in the program. For example, New York, Minnesota, Massachusetts, Rhode Island, and Louisiana have 14% of the U.S. population, but receive 31% of ICF-MR reimbursement. New York, Minnesota, and Rhode Island received more than $45 per state resident in ICF-MR reimbursements in 1985, while 8 states received less than $10. Assuming for the sake of demonstration that the ICF-MR program were paid for by the federal personal income tax paid by the citizens of each state and that federal revenues equalled expenditures, in FY 1985 New York, Minnesota, and Rhode Island were getting back more than 2 dollars for every dollar contributed, while 4 of the 10 poorest states in the nation were paying more into the ICF-MR program than they were getting back (WV, KY, GA, DC). In effect, citizens of Georgia and West Virginia were subsidizing services in New York and Minnesota. The irony of this happening under Medicaid should not be lost.

- In addition to the large institutional orientation of the ICF-MR program (exclusively a long-term care program), the Medicaid waiver is predominantly a long-term care program with only a third of total participants with developmental disabilities residing with their families and less than 25% of FY 1985 waiver expenditures going to services other than residential and habilitation (Laudecina & Burwell, 1985). Even including the Medicaid waiver program only one-quarter of the persons served by Title XIX programs for persons with developmental disabilities are in community settings and federal financial commitment to families with developmentally disabled members remains extremely limited.

In the 1987 Developmental Disabilities Act Congress expressed its desire to be of assistance in enabling persons with developmental disabilities "to achieve their maximum potential through increased independence, productivity, and integration into the community." It is important to recognize the dramatically different capacities of current policy and the bill being considered in providing these results. Evidence of these differences is cited below.

Independence. With respect to independence, there are two issues. The first regards independent functioning of persons in long-term care and second regards personal independence. With respect to independent functioning, there is a substantial body of fairly well designed research that compares changes in independent functioning of persons moving from institutional to community settings with control/contrast groups remaining behind. There are no inconsistencies in the findings. I quote a summary by a working group with the Department of Health and Human Services about these studies:

> "their findings are consistent and reflect important behavioral change clearly associated with movement from institutions to community-based living arrangements. More specifically, these studies demonstrate a consistent positive correlation between community integrated experience and the acquisition of adaptive behavior, particularly in the areas of self-care, social behavior, and communication... [T]here is substantial empirical data to support the philosophical and social principles of continued depopulation of institutional settings and the expansion of family and community care."

Certainly these findings more than justify S.1673's gentle prodding of states toward community-based settings in the name of increased independence. Admittedly this research includes only large public institutions. People associated with large private facilities may well challenge these findings as irrelevant to their particular situations. In response, one must ask what factors of environment or training are available in these private institutions, which on the average operate with about half the average per person funding of state institutions, to produce substantially better outcomes than their public counterparts.

Regarding the issue of personal independence, that is, autonomy and individual activity, our research on a national sample of 231 facilities found facilities of 8 and fewer residents providing significantly more autonomy and activity than larger facilities. Direct comparison of facilities of 15 and fewer, and 16 and more residents favored the smaller facilities in both areas.

Productivity. Regarding the productivity of persons with developmental disabilities, this bill offers obvious and important changes in federal policy in direct line with the goals of Congress. The improvements this bill makes in terms of support for vocational services are critical. In a number of recent studies, states have cited lack of consistent federal program support as a major impediment to implementing employment programs and opportunities for persons with developmental disabilities. Because vocational training and services is not covered under current ICF-MR policy, this bill offers major support to the Congressional commitment to productivity.

Integration. With respect to the interest of Congress in integration, research again offers unequivocal support of this legislation. Obviously small, community-based facilities, usually occupying existing housing in established neighborhoods, are better physically integrated into communities than larger institutional settings, which are typically physically segregated and invariably architecturally segregated. But at a deeper meaning of integration, do community-based facilities promote more social integration than larger facilities? The answer is clearly, yes. National research at our Center, statewide research in Illinois (Fujiura, Hemp, & Braddock, 1987) and a number of other studies of persons released from institutions show consistently that people living in community settings go to more movies, more restaurants, more stores, more sporting events. They go on more walks off the grounds of the facility and have more visits to friends away from the facility. They are more likely to participate in organized sports, including Special Olympics, to have friendships with nonhandicapped persons and to have more contact with their families. Even though they are not more likely to attend religious services, they are more likely to attend regular community churches. Generally, the only off the grounds activities they are not more likely to engage in are group field trips. However self-evident these findings may be, they represent important indicators of integration into the community. Congress has an opportunity to promote not just the physical integration of people with developmental disabilities, but their social integration as well.

Clearly Medicaid Title XIX needs a total overhaul to adequately serve persons with developmental disabilities. Policy developed in 1971 primarily to assure certain minimal standards of care and treatment to residents of large state institutions no longer reflects appropriate standards for services to persons who will ever more commonly be served in noninstitutional settings. A case can be made for judging that policy as having succeeded in realizing the goals set for it in 1971. But as an instrument for realizing our social commitments in 1988, it is clearly failing. Access to services is scandalously behind demand, with "openings" existing only in settings which fail to meet prevailing standards of appropriate service. The federal government plays a significant role in monitoring the quality of services for less than 60% of the persons with developmental disabilities in long-term care settings and much less for other types of services.

The present long-term care system is extremely inefficient in its allocation of resources. The bulk of funding goes to facilities which offer little promise of exhibiting habilitative "productivity," but whose costs of care ($50,000 per year per resident in state institutions) are growing far more rapidly (about 12% per resident per year) than more effective models of service. It is the obvious inefficiencies of present policy competing against the tantalizing promise of generous federal cost sharing that is the primary cause of the remarkable variation among states in utilization of the ICF-MR option, and therefore, in receipt of federal funds. In no way can present policy be construed as reasonably impelling change in the direction of currently espoused social values.

The Promise of S.1673

The Medicaid Home and Community Quality Services Act of 1987 would provide dramatic remedies of these shortcomings. It would move Title XIX federal program participation away from a single, uniform model of long-term care that reflects the perceptions and realities of 1971, to a comprehensive, individually-oriented program of services and protections responding to contemporary purposes and visions.

Freeze of federal funding to large institutions. It is important that this bill will commit no more federal funds for institutional care than are presently being spent. Those operating large facilities which are relatively good will know that the federal government has committed about 3 billion to such facilities, meaning that with the many clearly inadequate institutions, there will be ample opportunity for the better ones to survive. Indeed, even with the proposed freeze, this program would remain primarily an institutionally oriented program for some time to come. But the research showing the greater benefits of community living cannot be ignored by a Congress that claims commitment to the best interest of people with developmental disabilities.

Promoting of home and community services. This bill would greatly aid states in developing and maintaining community-based services programs. It helps states reflect the highest values and qualities of contemporary services, for which at present they are able to receive relatively little federal assistance. By separating federal financial participation for home and community-based services from existing levels of federal funding of institutional care, as the Medicaid waiver has required, this bill would represent a major stimulus for states to begin to deal with the sizable and growing waiting lists that have developed around the U.S. for community-based services. An October 1987 report by the Association for Retarded Citizens-U.S. (Davis, 1987) estimates about 60,000 persons with mental retardation nationwide on waiting lists for community residential services in the United States. Indeed, the two main products of current federal Medicaid policy are institutional services for those who will accept them and waiting lists for those who won't.

This bill would cover the most integrated residential options, including foster care and semi-independent living. It would cover the most culturally valued and cost effective daytime activities, those involving work. This bill would embrace the generally neglected segment of the developmental disabilities community, persons living at home and their families. The last major enactment of Congress with a major direct effect on families with developmentally disabled members was P.L. 94-142. Since its passage, or more specifically from 1977 to 1986, the number of children and youth with developmental disabilities in public and private mental retardation facilities decreased from 91,000 to 48,500. Continuation of such trends should be a goal Congress and this bill certainly is the best hope to achieve it.

At the present time the single most important federal support for community-based services comes from the Supplemental Security Income (S.S.I.) and Social Security Disability Insurance (S.S.D.I.) programs. But these programs are designed primarily to provide for basic subsistence, not to provide supervision, habilitation, and other needed services. Indeed, the average monthly federal S.S.I. payment is only about $10 per day. In short, the financial gap between Medicaid and S.S.I./S.S.D.I. funded community-based services is enormous and the fact that the former is used so little in the community, despite its dramatically more attractive reimbursement formula, demonstrates concretely the concerns about its appropriateness. S.1673 would, therefore, undoubtedly reduce substantially the huge disparities among states in the extent to which the federal government contributes to the costs of providing long-term care services for persons with mental retardation.

Improving quality assurance. Another important feature of this bill is that it reaffirms a role and commitment on the part of the federal government to stimulate minimal levels of quality in long-term care in community settings as well as institutions. As was noted, only about 20% of the total population of community residential facilities for persons with mental retardation nationwide are in facilities with ICF-MR certification. The quality assurance requirements of the Medicaid Home and Community Quality Services Act would represent a major departure from the present lack of federal attention to the quality of non-Medicaid community services, or for that matter, of those presently provided under the Medicaid Home and Community-Based Services waiver program, with its minimal quality-related requirements. Under the Medicaid Home and Community Quality Services Act, states would be required to develop and maintain a comprehensive quality assurance system that would cover the full range of residential and other services covered under its state plan. It also provides a needed separation between public agency service provision and public agency monitoring. The direct abuse of the quality assurance mission by state employees monitoring state agencies is probably much less than some contend, but there is no good reason for the federal government to support the opportunity for or appearance of conflict of interest.

The Issue Before Congress

Good federal policy for services to persons with developmental disabilities and their families should exhibit four characteristics. First, it should assure reasonable access to appropriate services to individuals who are eligible for and in need of them. Second, it should assure reasonable quality of services irrespective of the specific "placement" decisions made. Third, it should provide for cost-effective utilization of public resources. Fourth, it should stimulate the evolution of service options in socially desirable directions (i.e., to this Congress, living in typical homes and communities and accessing the generic services and institutions of those communities, having maximum opportunity for independence, productive activity, and social integration, including social experiences with nonhandicapped people).

These are the standards by which I hope you will reevaluate our federal commitment to people with developmental disabilities. There are two choices. The present program established in 1971 to make deplorable conditions in institutions less deplorable, and S.1673, which will do much to improve congruence between the values and goals espoused by Congress and almost all states and the programs and services available to people with developmental disabilities.

There are possible changes in this bill that I would support. For example, I would like to see this bill require permanency planning for children and youth with developmental disabilities as Congress required of child welfare agencies in the Adoption Assistance and Child Welfare Act of 1980. I wished the bill established or at least encouraged separate authorities for services to persons with developmental disabilities and those with later onset. On a personal level, I feel setting the definition of community living facility at three times normal household size is too large to fully promote integration and is too contrived. I believe the policy reflected in this bill is so far from medical assistance that I share with many people in the Department of Health and Human Services doubts about whether it really belongs in Medicaid. But these points are trivial quibbles in comparison with the huge good this bill represents. I fully and unequivocably support S.1673. This bill will permit us to move toward the end of this century with a financing and quality assurance program that will directly assist in what needs to be done in implementing the high goals of Congress as outlined in the DD Act of 1987. This bill does not create community, that is up to all of us an individuals and small collectives. But it does provide us with the opportunity to create communities that embrace people with disabilities as neighbors, friends, coworkers and fellow citizens. I believe with the assistance of this bill we can do precisely that. There really are only two choices: we will stay with a policy enacted in 1971 to raise the quality of care of persons in segregated institutions to a minimally tolerable level or we can adopt a policy that recognizes and promotes the rights of persons with disabilities to true membership in the culture into which they were born. Not supporting the latter choice means acquiescing to the former. To me that would be tragic.

THE MEDICAID FAMILY AND COMMUNITY QUALITY SERVICES ACT:

HOW DOES IT ADDRESS RESEARCH FINDINGS, QUALITY ASSURANCE, AND FAMILY SUPPORT?

Presented by:

Valerie J. Bradley, President
Human Services Research Institute

INTRODUCTION

During the past twenty years, the field of developmental disabilities has undergone enormous changes in expectations about the abilities of persons with developmental disabilities and the nature of the services they should receive. It has been an exciting period and one full of gratifying and important accomplishments. I have been a participant in as well as observer of these changes from a range of vantage points including a legislative staff person in California, consultant, and President of the Human Services Research Institute (for nearly 12 years). In the course of my work, I have been involved in a range of analyses of developmental disabilities service systems in Connecticut, New Hampshire, Massachusetts, Pennsylvania, Virginia, Georgia, Iowa, Arkansas, New Mexico, and Colorado.

There are three specific areas I would like to address that have particular relevance to your deliberations. First, I would like to review some of the major longitudinal research findings in the field of developmental disabilities and deinstitutionalization. Secondly, I would like to discuss the issue of quality assurance, the principles that should govern program monitoring, and the extent to which the Medicaid Family and Community Quality Services Act is responsive to those principles. Finally, I would like to review some of the issues surrounding the support of families with children with severe disabilities and the role that the legislation can play in enhancing that support.

RESEARCH

From 1979-1984, I was the co-principal investigator of a five year longitudinal study funded by the then U.S. Department of Health, Education and Welfare. The study was directed at the federal court-ordered deinstitutionalization of approximately 1200 persons with mental retardation and other developmental disabilities from Pennhurst State Center. The study design involved periodic assessment of the individuals affected, the feelings of the families, the response of the state mental retardation system, and the reaction of the community.

The results, briefly, were as follows:

1. People with mental retardation and other developmental disabilities who moved to the community showed growth in adaptive behavior ten times greater than the growth displayed by matched groups who remained at Pennhurst.

2. Prior to placement out of Pennhurst, 72% of families surveyed were opposed to placement. Following placement almost all families agreed with the value of community placement for their relative.

3. Negative reactions to the development of homes in the community diminished after the home was in place for six months or more.

4. Unit costs in the community fell into a lower range than the costs at Pennhurst and more service was delivered per cost unit in the community. Upon further analysis, these cost differences were the result of significant salary differences between Penhurst staff and private community providers.

5. Community homes rated considerably higher on scales of normalization and individualization than the living areas at Pennhurst.

6. Community providers did develop the capacity to meet the needs of people with more serious disabilities.

The findings regarding client growth have been replicated in other states. Specifically:

- In New Hampshire, individuals leaving Laconia State School gained an average of 8% on adaptive behavior between 1979 and 1985. In the area of vocational skills, they gained almost 20%.

- In Louisiana, class members in a suit brought on behalf of people with multiple disabilities gained an average of 7% in adaptive behavior.

- In Connecticut, individuals leaving Mansfield State School showed significant gains in community living skills between 1985 and 1987, displaying average changes of 4 points in adaptive skills, 8.1 points in vocational skills, and a 3.6 increase in challenging behavior.

These results, however, should not be taken out of context. Such improvements do not happen in a vacuum. They are associated with systems which, because of state policy and/or court order, have evolved a well-articulated "infrastructure" or series of administrative supports. These elements include intensive case management, individualized planning, technical assistance and training, stable funding, programmatic vision and a comprehensive quality assurance mechanism.

The Medicaid Family and Community Quality Services Act addresses all of these issues. It mandates on independent case management systems and spells out case manager responsibilities; requires technical assistance, training and competency-based personnel standards; clearly articulates a series of programmatic expectations; dictates a reasonable cost methodology; outlines requirements for an Individualized Habilitation Plan; and lays out a framework for a comprehensive quality assurance system.

QUALITY ASSURANCE

Quality assurance is a major ingredient in the success of community programs. It is not, however, one thing -- it is multi-faceted and comprised of multiple elements. Quality standards are dependent on a variety of inputs including the values that govern the system, empirical knowledge (research regarding best practices), and professional training. These viewpoints all become relevant in the design of standards and in the creation of a range of quality assurance alternatives and the identification of quality monitors. Finally, quality assurance systems should enhance as well as regulate.

In order to ensure that services are responsive and that people are not dumped into inadequate community settings, quality assurance systems should meet six objectives:

- To assure that providers of human services have the capability to provide an acceptable level of service;
- To assure that client services are provided consistent with accepted beliefs about what constitutes good practice;
- To assure that a commitment of resources produces a reasonable level of service;
- To assure that the services that are provided have the intended affect;
- To assure that the limited supply of services is provided to clients most in need; and
- To assure that the legal and human rights of clients are protected.

Current quality assurance systems in developmental disabilities are somewhat effective in meeting those objectives having to do with capacity and practice -- usually through licensing and accreditation. They are less effective in assessing cost effectiveness and service outcomes. The protection of legal and human rights has improved substantially over the past decade, but more responsive mechanisms are required.

The Medicaid Family and Community Quality Services Act sets out a quality assurance scheme that embodies the elements noted above. First, it does not assume that quality assurance is a uni-dimensional entity, but rather a function that must be accomplished through a variety of vehicles.

The proposed law includes requirements for federal oversight and validation; state licensing and/or accreditation; independent third party review of client progress and environments; and a case management system that is independent from service provision. The legislation also recognizes the importance of including multiple viewpoints. The law would subject all standards to public review, would require that family members participate in monitoring and that people with disabilities be canvassed regarding their satisfaction with services. This bill explicitly requires sixty days written notice before anyone is moved from a large facility to a community living facility or a family home. Finally, the bill stresses the enhancement of quality through training and technical assistance as well as the regulation of compliance.

The bill also meets the objectives of quality assurance. It ensures capacity and best practice through the inclusion of licensing requirements as well as the creation and review of individual client plans. It ensures cost-benefit by the establishment of a management information system to track services needed, services provided, and the costs of services and outcomes particularly in relationship to reduced dependency and increased productivity. Most importantly, however, it requires an assessment of whether people are better off as a result of receiving services. This stress on outcomes will assure that the individualized needs of people are being met and that any regression or loss of functioning is detected early.

Further, the bill focuses on the needs of those individuals with the most severe disabilities and those whose needs put them at risk of being placed in a more restrictive setting. Finally, the legislation includes strong protections for the rights of individuals and their families through strong appeal and grievance procedures, protective intervention services, and the inclusion of Protection and Advocacy services to resolve disputes and to investigate potential abuse.

The quality assurance scheme in the proposed bill is a "seamless web" of well articulated provisions. Each ingredient is interdependent and critical to the well-being of individuals in the community and to their growth and development.

FAMILIES

During the past twenty years, the norms and mores affecting American family life have undergone rapid changes. Parents of children with developmental disabilities have also endured these changes and additionally have experienced significant shifts in the way society responds to persons with developmental disabilities. Until recently these parents were afforded only two residential service options: they could forego traditional parental functions by placing their child in an institution or they could provide care at home with little or no external support. A third option, however, is slowly evolving -- the provision of a range of supports to families to enhance their care giving capacity and to meet the extraordinary responsibilities and requirements of their children with severe disabilities.

During a 1984-1985 national survey conducted by HSRI it was found that about 25 states offer what may be termed "extensive services" to families. Though it is clear that most of these statewide systems are embryonic and somewhat fragile enterprises, offering few services to relatively few families, there is an emerging commitment among policy makers to support families. Most statewide programs have been initiated since 1980 and state officials, pressured by a growing grassroots concern for supporting family efforts, are re-shaping existing programs (e.g., Oregon, Pennsylvania, Connecticut), or initiating new pilot or statewide efforts (e.g., Massachusetts, Colorado, Texas).

The emergence of family support is fueled by the increasing acceptance of three basic values:

1. All children, from birth to young adulthood, regardless of disability, belong with a family -- natural or otherwise -- and need enduring relationships with adults.

2. Families must receive the supports they need to maintain their child at home and to enhance their capacity to provide care.

3. Means for supporting family efforts must build on existing social networks and natural sources of support within the community.

Family support services, however, are still fragmented and inadequate to meet the need. The major federal initiative for families with children with serious health conditions, the "Model 50" or "Model 200" Medicaid Waiver program (formerly "Katie Beckett" waivers), exists in only 18 states. The number of children covered varies greatly from state to state, with some programs serving only one person and others serving the maximum number.

Further, families have reported in interviews with HSRI that local welfare offices frequently do not understand the program and that they have been treated with suspicion and contempt. In one state, families on the program were told that they would have to repay their benefits.

A failure to recognize and support families ultimately has a financial cost. With respect to the relative cost of home care for children with serious health conditions versus care in an acute care hospital bed, the figures show enormous savings when health care is provided at home. For instance, in 1984, Aetna Life and Casualty Company released figures showing savings of $3,558 per month for persons with severe cerebral palsy and uncontrolled seizures who were treated at home, and $40,761 per month for babies born with feeding or breathing problems who stayed at home. Due to findings such as these, there is growing interest among private health insurers and hospital administrators to make home health care a crucial element of their cost containment strategies.

Likewise, contrasts in the costs of care in an intermediate care facility for persons with mental retardation (ICF-MR) versus various family-based alternatives are equally dramatic. For instance, in a recent study of the public costs associated with residential care in Michigan, the annual cost per person of ICF-MR care was $63,722, compared to annual costs of $22,358 for specialized foster care, $25,215 for foster care with supplemental staffing, and less than $5,000 for services provided directly to the natural family.

Finally, the costs to the family in terms of stress and lost opportunities should also be figured into any calculation of cost-benefit.

What do families need? In the numerous surveys HSRI has conducted among families, the following specific supports for both family members and persons with disabilities were noted:

Home-Based Services Centered Around the Person with an Illness or Disability	Home-Based Services Centered Around Family Members
diagnosis and assessment	information and referral
educational/therapeutic services	temporary relief/respite
medical care (in/out-patient)	family counseling
home health care	parent/sibling education
recreational opportunity	day care
special clothing	housekeepers
special diets	cash assistance
transportation	futures planning
adaptive/medical equipment	mutual support groups
housing adaptations	adequate housing
adequate health insurance	case management

The strongest message that emerges from families is that there is no "magic bullet." Each family is different and has needs particular to their unique circumstances and resources. Further, the needs of families change as they and the family member go through the various developmental and life cycles. The proposed legislation recognizes the uniqueness of families and provides for a flexible menu of services that will empower and not supplant the family and their natural support systems.

The only area I would strengthen has to do with the deeming criteria related to parental income. Instead of an optional provision, I would require states to waive parental income requirements in determining eligibility for family support services. This will ensure that many families will not be pushed to the brink of financial and emotional collapse before becoming eligible for services. It will not perpetuate the current, perverse financial incentive to break up families by placing children in out of home settings.

CONCLUSION

- Research supports the assertion that all people regardless of severity of disability can grow and develop in the community. The Medicaid Family and Community Quality Services Act provides the necessary service infrastructure to ensure that these results are replicated around the country.

- Quality assurance in the community requires different and varied approaches to protect the well being of individuals with serious disabilities. The legislation lays out such a blueprint.

- The needs of families with children with severe disabilities and serious health conditions are wide ranging and idiosyncratic. The bill recognizes the breadth and diversity of these needs.

I urge you to act on this legislation for Medicaid reform this year. A decision to do nothing and leave the ICF-MR program intact is a disservice to persons with disabilities, their families, society and public policy.

STATEMENT OF TESTIMONY
on the
Medicaid Home and Community Quality Services Act of 1987

by

Ronald Welch

Associate Commissioner, Maine
Department of Mental Health and Mental Retardation

March 22, 1988

I. INTRODUCTION

My name is Ronald Welch. I am the Associate Commissioner of the Maine Department of Mental Health and Mental Retardation. I also serve as the President of the National Association of State Mental Retardation Program Directors. Today I appear before the Subcommittee as a representative of the Association. The membership of NASMRPD consists of the designated officials in the fifty states and territories who are directly responsible for the provision of institutional and community-based services to a total of over half a million children and adults with developmental disabilities .

According to statistics compiled by the Institute for the Study of Developmental Disabilities at the University of Illinois-Chicago, federal Medicaid payments totalling $2.9 billion were channelled to the states in FY 1986[1] on behalf of 143,815 residents of intermediate care facilities for the mentally retarded (ICF/MRs).[2] Of this total, $2.1 billion was expended in large public and private institutions (15 beds or more), while the remainder was obligated for community-based residential services. An additional $246 million was claimed by the states for non-institutional long term care services on behalf of Title XIX-eligible persons with developmental disabilities,[3] including an estimated $161 million[4] for homes and community-based waiver services to an estimated 24,000 individuals.[5]

Federal Medicaid payments now consititute 34 percent the aggregate revenues received by state MR/DD agencies for institutional and community-based services -- up from 19.3 percent in FY 1977.[6] It should be obvious from these figures that the members of our Association have a vital stake in the future evolution of federal Medicaid policy.

II. MAJOR TRENDS IN PROGRAMMING FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

Over the past decade, historic changes have occurred in the states' approaches to serving persons with mental retardation and other developmental disabilities. These changes are reflected in both the steady decline in the number of persons served in large, state-operated institutions (from 149,176 in FY 1977 to 100,421 in FY 1986) and the increasing proportion of public dollars expended on community-based services. Between FY 1977 and FY 1986, total expenditures by state governments for such services increased from $910 million to $4.4 billion (excluding federal income maintenance payments), or by 484 percent. By FY 1986, states, on average, were spending practically half their budgets (48.8%) on community-based services -- up from 23 percent in FY 1977. During this period, the number of states spending 50 percent or more of their MR/DD budgets on community services grew from two to thirteen.[7]

Meanwhile, over the past four years, states spending in institutions and other large congregate settings has declined slightly, when measured in real dollar terms, despite the continuing increase in the average per capita cost of state-operated residential facilities (from $90.57 a day in FY 1982 to $126.79 a day in FY 1986).[8] This decline has been more than offset by increased spending on community programs, where the average rate of increase has been 19.3 percent over the past nine years.[9]

We are in the midst of a major reconfiguration of the delivery of services to persons with developmental disabilities in this country. In the area of residential services, the use of large, multi-purpose congregate care facilities is being deemphasized in favor of small, integrated community living settings. In day services, the trend is toward expanding integrated employment opportunities for adults with developmental disabilities and tailoring services and supports to the specific needs of persons who are unable to work. And, generally, our mission is not to serve as caretakers but rather to assist citizens with disabilities to achieve their own optimal degree of independence as well as a self fulfilling role in society.

III. LEGISLATION TO RESTRUCTURE MEDICAID

The purpose of today's hearing is to consider a bill to restructure Medicaid eligibility, coverage and long term care benefits applicable to certain persons with severe disabilities. This measure (S. 1673) was introduced last September by Senator John Chafee (R-RI). Called the "Medicaid Home and Community Quality Services Act of 1987", S. 1673 would require the states to cover a wide range of "community and family support services" under their Medicaid plans. Federal financial participation in the cost of larger ICF/MR facilities (i.e., those with 16 beds or more) would be frozen at a base year level in order to offset part of the additional federal costs of covering community and family support services under the Medicaid program and also to give the states further incentives to develop such services.

The National Association of State Mental Retardation Program Directors strongly supports the enactment of the "Medicaid Home and Community Quality Services Act of 1987". Our support for this legislation is based on a careful analysis the implications of S. 1673 and a recognition that it would rectify many of the fundamental defects in current Medicaid policy.

More specifically, Senator Chafee's bill would:

- Eliminate the institutional bias inherent in current Medicaid law with respect to long term care services for persons with severe disabilities. By placing community and family support (CFS) services on an equal footing with institutional long term care service options under Medicaid (i.e., ICF/MR, ICF and SNF), Congress would be equalizing the financial incentives and, thus, increasing the prospects that eligible persons will be served in the most appropriate setting.

- Grant the states greater flexibility in using federal Medicaid dollars to achieve long range, systemic reforms in services to persons with severe disabilities originating early in life. One of the major barriers the states face to restructuring existing state-local service delivery systems is the built-in contradictions and discontinuities in existing Medicaid policies. S. 1673 would address this problem by requiring each state to develop a detailed, statutorily prescribed roadmap describing how it intends to carry out its responsibilities for providing community and family support services. The Secretary of Health and Human Services would have responsibility for overseeing state implementation activities, but he would be prohibited from engaging in the types of federal micro-management that often occurs under the Medicaid HCB waiver program.

- Shift the emphasis of Medicaid funding toward habilitation services that assist individuals with severe disabilities to achieve greater independence and assume productive roles in American society. One legitimate criticism of current Medicaid policy is that it fosters continued dependency. The long-standing regulatory prohibition against Title XIX payments for vocational training services acts as an impediment to transitioning such persons to remunerative work, despite the fact that we now have solid data to document the fact that persons with severe disabilities can be productive workers if they are furnished with appropriate training and, most importantly, ongoing support services. S. 1673 would rectify this defect in existing law by requiring the states to cover "specialized vocational services" as one element of the community and family support services offered under their Medicaid plans.

- Clarify the relationship between educational and Medicaid funding on behalf of school-aged children with severe disabilities. Present HCFA/HHS policies prohibit a state from claiming Medicaid financial participation in the cost of any services to a school-aged child with a handicapping condition if the service is, or could be, identified in the child's Individualized Education Program, as required under the federal Education of the Handicapped Act. The effect of this policy is to foust off on state and local educational agencies costs for health-related services to Title XIX-eligible children that otherwise would be recoverable through the state's Medicaid program; or, worst yet, to simply deny such children access to needed services. This inequitv would be corrected under S. 1673 by distinguishing between "educational services" and "educationally-related services", with only the latter treated as Medicaid-reimbursable costs.

- Offer families expanded incentives to choose home-based care. Current Medicaid policy provides a family of a person with severe disabilities with perverse incentives; if they place their son or daughter in a Title XIX-certified institution (i.e., a SNF, ICF or ICF/MR), Medicaid will consider only the affected individual's resources in determining his/her eligibility and, thus, usually assume the total cost of the individual's care; if, however the family elects to care for their son or daughter at home, they assume full financial liability unless their income and resources are below the state's Medicaid eligibility levels (which, in many states are considerably below the official poverty line). One effect of this policy is to inflate the demand for the most expensive type of Medicaid service -- comprehensive residential care. S. 1673 would address this problem by: (a) expanding the existing state option to waive parental "deeming" under Medicaid (i.e., the attribution of family income/resources in determining the eligibility of a disabled child), thus allowing states to increase the number of such children who would be entitled to Title XIX benefits; and (b) requiring states to cover "individual and family support services" as one element of the community and family support services offered under their Medicaid plans.

- Provide states with greater flexibility in designing and financing out-of-home care services through their Medicaid programs. Small, community-based residences represent the fastest growing component of the ICF/MR program. While such facilities offer residents greater access to independence and community integration, they still represent a relatively costly model of service because they are tied to a facility-based approach to providing 24-hour care, supervision and services. One important lesson that can be drawn from the states' experiences with the HCB waiver program is that even persons with complex service needs can be served appropriately -- and often at significantly less cost -- in a non-facility based residential setting, provided proper support services are made available. The Chafee bill would build on these promising new developments in our field, by allowing the states increased latitude in financing various community-based residential service models through their Medicaid programs.

- Establish a fixed point of responsibility for overseeing federal Medicaid policies affecting persons with severe disabilities within the Health Care Financing Administration. S. 1673 would eliminate the existing policy vacuum within HHS by creating within HCFA a Bureau of Developmental Disabilities Services. This Bureau would be responsible for preparing and executing all federal Medicaid policies governing the provision of ICF/MR services, community and family support services and services provided under HCB waiver programs to persons with severe disabilities.

- Allow the Governor of each state to assign responsibilities for performing specific management functions related to the provision of community and family support services to agencies other than the single state Medicaid agency. This provision of S. 1673 is intended to facilitate the establishment of more effective methods of managing the delivery of Medicaid-reimbursable services at the state level.

While NASMRPD wholeheartedly endorses S. 1673, there are several provisions of the bill which we feel should be modified. Specifically, the bill should be amended to:

- Limit the maximum age of onset of a qualifying disability to 22. S. 1673, as introduced, would increase the age of onset threshold by one year for each additional fiscal year the legislation was in effect after FY 1986, until it reached a maximum level of age 50. While NASMRPD recognizes the importance of identifying appropriate loci of public responsibility for financing services to individuals who are severely disabled during adulthood, we do not believe that the present legislation is the proper vehicle for resolving this complex social issue. The bill is basically designed to restructure Medicaid policy as it impacts on persons with developmental disabilities. Fundamental conceptual and structural changes would be necessary to accommodate the needs of other disability target populations; in the process, the original legislative aims might be lost or diffused. Besides, at present, little is known about the number of non-elderly persons requiring long term care services due to a severe disability originating in adulthood, including the types of services they require, the estimated federal-state costs associated with furnishing such services and Medicaid's current and potential role in meeting the needs of such individuals. Under the circumstances, NASMRPD feels that the enhancement of Medicaid eligibility/service coverage for disability groups other than persons with developmental disabilities should be considered through separate legislation.

- Exempt publicly administered case management systems from the prohibition against lodging this responsibility with a provider of direct services. NASMRPD agrees, in principle, that responsibility for case management services should be separated from responsibility for direct services to eligible recipients. We also agree that each state should be required to spell out, in its implementation strategy, how such organizational independence will be maintained and potential conflicts of interest avoided, as would be required under Section 1921(d)(5)(F) of S. 1673. However, many states, historically, have provided MR/DD case management services through a state or county agency which also is the focal point for the provision of other direct services. Most experts feel that a public agency is able to carry out its statutory obligations more effectively if it has direct responsibility for this important gatekeeping function. Besides, there is no empirical evidence to suggest that these models for providing case management services are any more prone to conflicts of interest than occur under other models. Therefore, NASMRPD believes the legislation should give states the latitude to designate public agencies as providers of case management services to individuals receiving community and family support services, even if they also are responsible for the provision of other direct services.

- Explicitly permit states to claim amortized capital expenditures as part of any extraordinary housing costs that may be attributable to a person's disability. Under Section 1921(a)(3)(A) of S. 1673, a state would not be allowed to bill Medicaid for room and board costs except when temporary accommodations were necessary to fulfill a recipient's service goals or "... to cover extraordinary costs of food or housing attributable to the disabling condition of a particular individual or individuals". NASMRPD feels that the legislation should make it clear that a state may claim Medicaid reimbursement for the amortized costs associated with any capital expenditures that may be necessary to construct or renovate specialized housing designed to meet the particular needs of CFS service recipients.

- Delete the authority which would grant individual recipients the right to seek injunctive relief in federal court. Section 6 of the Chafee bill would authorize "any person injured or adversely affected or aggrieved..." by an action of the state administering agency to file suit for injunctive relief in federal district court. This unprecedented authority, in NASMRPD's opinion, would violate the separation of powers clause of the U.S. Constitution and could easily result in lengthy, time-consuming, costly litigation that would tend to divert resources from the primary goal of the legislation -- i.e., improving the quality and accessibility of services to eligible CFS recipients. Adequate avenues for seeking administrative and judicial redress would exist in the absence of this authority, through the appeals mechanisms required under the bill, the activities of state protection and advocacy agencies, state courts and, in the case of class action suits, the federal courts. We, therefore, recommend that Section 6 be deleted from the bill.

* * * *

On behalf of the Association, I want to express to the Subcommittee my appreciation for this opportunity to offer our organization's views concerning the "Medicaid Home and Community Quality Services Act of 1987" (S. 1673). If we can be of further assistance to the Subcommittee when this legislation is marked up, I hope you will call on us.

FOOTNOTES

1. Braddock, David, Richard Hamp and Glenn Fujuira, Public Expenditures for Mental Retardation and Developmental Disabilities in the United States: State Profiles (Second Edition), Monograph No. 29, Public Policy Monograph Series, Institute for the Study of Developmental Disabilities, University of Illinois at Chicago, September, 1986.

2. K. Charlie Lakin, Bradley K. Hill, Carolyn C. White and Elizabeth A. Wright, Medicaid's Intermediate Care Facility for the Mentally Retarded (ICF/MR) Program: An Update, Report No. 25, Center for Residential and Community Services, Minnesota University Affiliated Program on Developmental Disabilities, University of Minnesota, November, 1987.

3. Braddock, et. al, Ibid.

4. Memorandum from Brain Burwell, Systemetrics/McGraw-Hill Healthcare Group, entitled "FY 1987 Expenditures for Home and Community-Based Services", Dated March 4, 1988.

5. "Executive Summary, Report of the Working Group on Improving Federal Policies for Persons with Mental Retardation and Developmental Disabilites", U.S. Department of Health and Human Services, March, 1988.

6. Braddock, Ibid.

7. Ibid.

8. Lakin, et. al, Ibid.

9. Braddock, Ibid

Public Hearing of the U. S. Senate Finance Committee
Concerning
Senate Bill 1673
The Medicaid Home and Community Quality Services Act of 1987

Testimony of the Voice of the Retarded, Inc.
P.O. Box 1395
Palatine, Illinois 60078-1375

Presented by
George L. O'Donnell, 2nd. Vice President

Mr. Chairman, and members of the Committee, my name is George O'Donnell. I am providing this testimony on behalf of the Voice of the Retarded, a nationwide organization of parents, guardians and friends of developmentally disabled persons who reside in over 50 public and private residential facilities throughout the United States. We express our sincere appreciation to the Committee for granting us this opportunity to present our views.

Basically, we are opposed to Senate Bill 1673 for the following reasons:

FREEZING FEDERAL FUNDS

The Medicaid benefits of all "individuals with a severe disability", who reside in facilities of over 15 beds in size, are to be frozen as of the time of enactment of this bill. As a result of such "freeze", only those costs for inflation which actually exceed six percent per year would be reimbursed.

When, as a result of limiting federal funding in this manner, the inevitable decertifications of these facilities begins to occur, additional funding would be provided only in conjunction with a "reduction plan" whereby all, or part, of the facility would be closed.

We have profound concerns as to the chaotic situation which would be precipitated as a result of such procedures.

MANDATORY TRANSFERS

In addition, this bill proposes to implement a mandatory transfer program.

Regardless of the degree of their disability, or the nature of their needs for medical assistance, all "severely disabled individuals" being cared for in facilities of over 15 beds in size would be subjected to the terms of a state "implementation strategy", whereby, after enactment of this bill, they would be involuntarily transferred to a facility of less that 15 beds in size.

In our judgement, all mentally retarded persons should not be forced to reside in facilities of less than 15 beds, because the diverse service needs of this population precludes the imposition of such arbitrary restrictions on their care and treatment.

DENIAL OF FREEDOM OF CHOICE

This bill also proposes to deny severely disabled individuals their freedom of choice with regard to the selection of service providers.

While all other disabled persons eligible for medical assistance under the terms of the Medicaid program would continue to be afforded freedom of choice, as is presently provided under the terms of Title XIX, all "severely disabled individuals", as defined in this bill, would be specifically denied this right.

In our judgement, there is no logical justification for discrimination of this type against a defined group of disabled individuals.

STATE CONTROL OVER STANDARDS AND MONITORING

While federal authorities will be required to continue their "look behind" surveys of so-called "large facilities", and take prompt action to decertify them for non-compliance, in relation to approved, very specific federal standards of care, this bill would place both the promulgation, and monitoring, of standards for so-called "small facilities" entirely in the hands of the states. Past experience with various "nursing home programs" fails to provide sufficient assurances that proper service standards will be maintained, unless appropriate federal controls are in place.

INDISCRIMINATE LIMITATIONS ON "CLUSTERS" OF GROUP HOMES

Whereas some intermediate care facilities are designed as group home "clusters" which provide homelike environments for many mentally retarded individuals, wherein they learn the skills necessary for social adjustment, this bill would definitely limit such "clusters" to homes which were in operation as of September, 1987, had no more than eight beds per home, and were in "clusters" containing no more than three such homes.

In our opinion, these restrictions would tend to discourage the development of facilities specifically designed to provide a means for encouraging the skills necessary to facilitate community living, a stated objective of this legislation.

DEINSTITUTIONALIZATION OVERLAY

In general, Mr. Chairman, Senate Bill 1673 proceeds from a fallacious logic which states: All "large facilities" are "bad". This is a "large facility". Therefore, it is "bad". When a "large facility" is defined as anything over 15 beds which serves "individuals with a severe disability", the tendency is to create a huge, controversial deinstitutionalization program which is counterproductive to the stated purposes of this legislation. In our opinion, this deficiency permeates the entire bill, creating problems which would be very difficult to correct by routine amendment procedures.

COSTS

It has been said that, should Senate Bill 1673 be enacted, the federal government will "save money". We are told that these savings will accrue, because the Medicaid benefits of the residents of "large" facilities will have been "frozen". Thus, it is alleged that projected increases in costs due to inflation will not occur, and money otherwise allocated for "institutions" will be used to defray the costs of proposed "community" services.

However, to date, no cost estimates have been provided to substantiate these claims. We understand that the Congressional Budget Office has made a preliminary estimate, but that this study has not been released.

Likewise, to date, we understand that the Office of Management and Budget has reviewed this legislation, but that no cost estimates are available.

Therefore, the Voice of the Retarded has initiated, and published, a cost study which utilizes certain data provided for this Committee by the Library of Congress. (1)

As of 1986, there were 158,616 mentally retarded and similarly disabled persons being served in intermediate care facilities for the mentally retarded, (ICF/MR), in the United States.(2)

However, there are approximately 377,000 persons, who could be eligible for ICF/MR services, if such services were made available. To quote the Library of Congress, "This number is based on an estimate of the number of severely and profoundly retarded persons in the U.S., on the assumption that ICF/MR services are most appropriate for this population". (3)

If the 377,000 who are not being served were to receive appropriate services as a result of the enactment of S. 1673, it is therefore obvious that the costs to cover the total group of over 500,000 persons actually in need of this service would be at least double the cost currently being experienced to serve only 158,000 of this total.

The problem is not to be solved by simply closing "large" facilities and reallocating current costs. Fundamentally, it is necessary to determine the total number of disabled persons found to be in need of appropriate services, and then adopting rational policies and providing sufficient resources to meet those needs.

Therefore, the Voice of the Retarded recommends that Senate Bill 1673 be set aside, and that a positive proposal be developed which would avoid the tendency to embrace such regressive measures as "freezing" Medicaid funds, placing "limitations" and "restrictions" on "large facilities", mandating transfers and denying disabled persons their right to freedom of choice. In our judgement, these proposals only serve to exacerbate the problem.

We propose that an array of residential services be made available, including foster homes, group homes and intermediate care facilities, depending on the needs of the individual, and we stand ready to cooperate with all interested parties in achieving this goal.

AUTHORITIES ENDORSE PRESIDENT'S REPORT

In conclusion, Mr. Chairman, it is our judgement that any legislation enacted in the area of mental retardation should recognize the long-standing, basic goals established by a very respected, well documented public report.

Recently, Dr. George Tarjan, an eminent authority in the field of mental retardation, while addressing a group of parents at Bethesda Lutheran Home, in Watertown, Wisconsin, strongly endorsed the "continuum of services" concept which was first proposed by the monumental study, "National Action to Combat Mental Retardation", sponsored by the late President John F. Kennedy. (4)

Dr. Tarjan, and other eminent authorities, refer to this work as a classic in the field of mental retardation. Yet, unlike this proposed legislation, President Kennedy's report strongly endorses a comprehensive service system, complemented by high quality intermediate care facilities.

A further example of expert thinking in this area was recently provided by Dr. Edward F. Zigler, Sterling Professor of Psychology, at Yale University. On the occasion of receiving the Edgar A. Doll award from the American Psychological Association for his contributions to the field of mental retardation, in August, 1987, Dr. Zigler stated, in part, that the logical "middle ground" with regard to some of the issues we are contemplating here today is, quote, "to aim at providing a continuum of services". Dr. Zigler goes on to say that, "Available options should range from family care to placement in large institutions, depending on the characteristics and abilities of particular retarded individuals and their families." (5).

Mr. Chairman, the Voice of the Retarded joins professors Tarjan and Zigler in these judgements. We do not believe that national legislation should be based on a dubious set of principles which maintain that all "large" facilities are "bad", and all "small" facilities are "good". A much more positive approach, in our opinion, would be to develop an array of residential services, designed to meet the needs of all mentally retarded persons.

Again, our thanks to you, Mr. Chairman, and to the members of this distinguished Committee, for the opportunity to express our views. We shall be pleased to respond to your questions.

Notation:

1) "Analysis of Senate Bill 1673", October 15, 1987
   Voice of the Retarded, Inc., P. O. Box 1395,
   Palatine, Illinois, 60078-1395

2) Smith, Mary F., and Price, Richard,
   "Services for Persons with Mental Retardation and Developmental Disabilities: Background Information and Discussion of Issues",
   The Library of Congress, Congressional Research Service,
   September 16, 1986, page 34.

3) Ibid, page 30.

4) "National Action to Combat Mental Retardation",
   The President's Panel on Mental Retardation,
   U. S. Govt. Printing Office, October, 1962.

5) Zigler, Edward F.,
   "From Theory to Practice",
   Address to The American Psychological Association,
   Annual Convention, August, 1987.

W. ROBERT CURTIS, M.P.H., Sc.D., J.D.
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ON BEHALF OF THE
CONGRESS OF ADVOCATES FOR THE RETARDED, INC.

REGARDING THE

MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT OF 1987

MARCH 22, 1988

FACTUAL BACKGROUND

I come here today to share a single observation; one quite simple in its concept but one having enormously far-reaching implications. I offer it not as an advocate for any point of view but rather as a professor and scientist who has stepped back to reflect on a twenty year career as a clinician and manager in the field of developmental disabilities and mental health care. Having finally understood this concept I will never forget it. And I believe you cannot ignore its implications in general on society. Today I ask you to consider specifically how Senate Bill 1673 will affect the existence of a 150 year old covenant.

Let me approach my observation about this covenant from the perspective of parents of retarded children. Becoming the parents of a disabled child, especially a severely disabled child, is the most devastating event to occur in a family short of death itself. It is devastating because of the time and resources demanded from the nuclear family, which we all know is now rather barren when compared to the extended family of the past and strains today even more under two wage earner requirements.

I have not personally experienced this devastation because I am not the parent of a disabled child. Rather I know it from searching in the eyes and lives of hundreds of parents over the last twenty years. I've cried with them for a few moments but I have not had to cry day after day with no end to the tears. What I am saying is this: Those of us working in the field recognize this tragedy in an intellectual way but only a few genuinely experience the complete and permanent injury of nature's cruelest blow to the family.

As we well know every state in this union has responded to this tragedy. Long before there was even a thought about national human service programs, states built institutions as a place where severely disabled children could live when their families could no longer shoulder the burden of 24 hour care. Back then everyone recognized that someone other than families had to make the substituted decisions that nondisabled children soon learned to make on their own. This is the essence of a state institution. First and foremost it provided an organization that delivered substituted decision-making for disabled individuals. Not some of them but *all* 530 institutions were financed and built by states in order to take over substituted decision-making when a family could or should do it no longer. State institutions saved families, thousands of families every year.

In a organized way, and one noted for its stability, state institutions still not only provide shelter, food and care for disabled individuals but they, through their workers, make the decisions about daily living that are essential to the survival of mentally disabled individuals.

In fact state institutions are so stable and so connected to the fabric of society, that twenty years of intense deinstitutionalization has achieved two basic outcomes: the creation of a wide range of community-based programs for less disabled individuals and a demoralized work force at many state institutions.[1] Simply stated, institutions for the mentally disabled remain as each state's single largest expenditure and for many families the state's single most important program.

It is clear why so many parents are thankful that these institutions still remain in place. But why is it that a growing number of parents have become so outraged with federal legislation that intends to change these institutions? The answer to this question is not obvious on its face. My "simple" observation explains why this is so. The covenant created between families of disabled individuals and the state is now under threat.

THE CREATION OF A COVENANT

Each time one of the 530 state institutions was built, or new buildings were added on an existing site, years of planning was required from citizens, parents, administrators and state officials. As the new institution or new building came into being it symbolized the covenant between the parents of a disabled child whose physical custody eventually had to be released, and the state which funded and managed the services that replaced the parents' support and decision making. This covenant recognized the transfer of substituted decision-making from family to state. Everyone understood that there would be continuous care for a mentally disabled child, or what was often the case, a disabled young adult.

This covenant reflected state government's most noble deed. The state essentially said it was alright for families to be released from this burden. It was alright to turn time and resources back to picking up the pieces of family life after long years of sacrifice. Under this covenant the state willingly stepped into the worn shoes of family members and began exercising its own *parens patriae* authority directly on behalf of the disabled individual. No matter how ambivalent or guilty parents felt about giving up custody of their child, the state not only understood why it was necessary, it promised lifetime care, in most cases extending even beyond the life of each parent.

The history of this covenant is moving beyond belief. But it runs deepest for those families with only moderate means and a severely or profoundly impaired child. Listen to their profound ambivalence and personal stories before enacting a law that might destroy this covenant. Read the deeply moving records written by some of the professionals who picked up substituted decision-making in each state institution over the past century. Examine the legislative records that document the intent of a state when a new institution was created. Until recently everyone understood this covenant. But now, with the deinstitutionalization movement still out of control, some professionals continue to replace this covenant with their own ideals and values.

For me the covenant is best expressed on a brass plaque attached to a building in 1925 that recognized then the hundred years of services by Western State Hospital, one of the oldest state institutions in Virginia as well as this nation. Fourteen simple words captured the essence of the covenant symbolized by state institutions: "He shall cover thee with his feathers and under his wings shall thou trust."

THREATS TO THE COVENANT

Even during the last two decades of deinstitutionalization, families have continued to extend their trust to states under this covenant. In fact the transfer of higher functioning individuals out of state institutions to community programs did not severely threaten the trust placed in state government. Often the covenant became even more meaningful to families as the state provided a broader range of care for disabled individuals who benefitted from these services. Few argued against community programs where there was genuine potential for exercising greater individual liberty and real benefit for the disabled individual experiencing integration in community activities.

Some concern however did arise about the principle vehicle states used to add community services to its continuum of care: the private agency working under contract to the state. No doubt the private agency approach to community care was practical for most states. But families began to worry about the identity of these individuals who were taking over substituted decision-making for their children. And the rationale for "going private" offered by state officials at times seemed contrary to what families had become accustomed to at state institutions. Now there would be "competition".Services would become more "efficient". Cash flow, profit or economic growth would become part of everybody's decision-making, clinical or administrative. It seemed that the "best interest" criteria so central to substituted decision-making might be replaced with economic criteria.

This worried families. When family members could no longer find an equivalent of the superintendent, the one person who was ultimately responsible for all of the substituted decisions, family members became concerned again. When it was even difficult to find a middle manager, someone from a private program who oversaw all the hour by hour decisions made about sleeping arrangements, clothing, food, medication, health care, recreational activities, day programs, and problems with other residents, families became even more concerned.

There seemed to be no accountability in the private sector. Decisions were dispersed and no one person was responsible for the total best interest of their child. Disabled individuals seemed to just get swallowed up by tiny programs whose operations were more dependent on *transportation* services than good will or the caring given so freely at state institutions by direct care workers.

And perhaps most troubling of all these tiny programs seemed unstable. Direct care staff and managers were continually turning over while the organization itself was in constant change. These were simply not good conditions under which family members could be asked to extend trust to the state for the life of their family member.

The real test of these new private community programs came when family members approached state elected officials with their concerns. Here family members expected to hold their elected representatives responsible for state government decisions to alter the covenant. But political accountability it seems is as elusive under the private agency approach as administrative accountability. The private sector simply is not directly accountable to elected officials. It is too far removed by contracts with the executive branch and is often out of control because of financial incentives created at the national level.

The creation of a private sector in which there is no stable locus for substituted decision-making, if at all, and one which elected state officials cannot hold responsible looks like disaster to families of the mentally disabled.

FEDERAL INTERFERENCE WITH THE COVENANT

Senate Bill 1673 threatens to add a second injury to families who are already reeling under the harm dealt to them by nature. The financial incentives built into this legislation are intended to pressure states to phase out their institutions for the mentally retarded. This legislation is nothing less than an intentional interference with the 150 year old covenant between states and families of the mentally retarded, a covenant that hundreds of thousands of individuals still rely on each day.

To the extent that advocates for this legislation believe families can transfer substituted decision making to a new private system located in the community, they are mistaken. The community system is too dispersed and too unstable. Furthermore, the private sector is unresponsive to elected officials if not also to the very state executives who review the thousands of contracts each year. Could it be clearer? This legislation says it is not alright to be released from the burden of decades of 24-hour care.

Family members should not be forced to choose *between* state institutions and an uncertain, unpredictable private sector when transferring the responsibility for substituted decision-making for their child to the state. This is a breach of covenant. If federal legislation encourages such a breach with financial incentives, then the federal government would be interfering with the oldest and most valued covenant between each state and its citizens in need.

Instead, states should be encouraged to maintain this covenant. Federal legislation which expands services to the mentally disabled must recognize that *the covenant* and *the institution* are the essence of a caring society and the foundation for comprehensive services. Additional services should be added on to this foundation, as had been done largely to date, not set out to deliberately destroy the foundation.

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[1] I have written elsewhere about the unintended harm of deinstitutionalization. See, for example, "The Deinstitutionalization Story," in *The Public Interest*, Number 85, Fall 1986, or "Commentary," in *New England Journal of Human Services*, Volume VII, Issue 4, 1987.

RESPECTFULLY SUBMITTED

BY

ASSOCIATION FOR RETARDED CITIZENS OF THE UNITED STATES

WITNESS:

JANELLE JORDAN

FIRST VICE PRESIDENT

ARC/TEXAS

TUESDAY, MARCH 22, 1988

I. INTRODUCTION

The Association for Retarded Citizens of the United States is a national voluntary organization composed of parents, educators, professionals in the field of mental retardation, people with mental retardation, and other concerned citizens. The ARC, in existence since 1950, has approximately 160,000 individual members in some 1,300 local and state ARC chapters nationwide. A recent membership survey reveals that two-thirds of ARC members are parents, foster parents, guardians, or relatives of persons with mental retardation. The ARC is the largest organization in this country representing and promoting the rights of individuals with mental retardation and their families.

The ARC has long advocated for reform of the Medicaid program as it affects long term care for persons who are developmentally disabled. We appreciate this opportunity to present testimony in wholehearted support of S. 1673, the "Medicaid Home and Community Quality Services Act of 1987."

II. BACKGROUND

The ARC has long recognized a need to reform, in two basic ways, the Medicaid program as it affects long term care for persons with developmental disabilities . First, the program needs to be altered to allow states more flexibility in providing individualized services to persons residing in their own homes, in family homes, or in small, family-scale, community settings. Secondly, the program needs to be altered to remove the heavy bias toward institutional service settings which exists in the current program. As a result of the recognition of the need for systemic reform, ARC supported reform measures in the 98th and 99th Congresses entitled the "Community and Family Living Amendments" (CFLA) of 1983 and 1985, respectively.

On September 19, 1986, the Finance Committee's Subcommittee on Health held a hearing on "The Medicaid Program and Long Term Care Services for Persons With Developmental Disabilities." At that time, ARC submitted testimony which reviewed the history of institutional residential services for persons with mental retardation and the impact of that history on the current Medicaid long term care program which relies primarily on a 24-hour model of institutional service. ARC stated then and continues to hold the position that institutions have proven unsuccessful in providing essential developmental opportunities needed by persons with mental retardation. National ARC policy calls for the eventual replacement of institutional services with appropriate community services over time. The ARC's 1986 testimony also reviewed the current and accepted philosophies and practices of service provision and how those principles are in conflict with current Medicaid policy in the Intermediate Care Facilities for the Mentally Retarded (ICF/MR) and the Home and Community Based Care (HCBC) Waiver programs. We also reviewed several principles and concepts which we believed needed to be a part of any Medicaid reform product.

Rather than review again the points made in previous testimony, we respectfully urge Members of the Committee to refer to our previous testimony for a thorough review of the ARC's significant interest and concern in this area. This testimony will not repeat the previous points; rather it will discuss ARC activity regarding Medicaid reform since the September 1986 hearing and ARC's support of S. 1673 as a vehicle for achieving the reforms called for in previous testimony.

In the fall of 1986, particularly as a result of the Health Subcommittee's hearing, it was clear that many major national organizations were in agreement that significant reform was necessary in the Medicaid approach to long term care services for persons with developmental disabilities. It was also clear that there was not agreement that the approach taken in the "Community and Family Living Amendments of 1985" was the best one. The CFLA bills in 1983 and 1985 had proven to be very controversial and the debate sparked was considered by the ARC to be a good means of airing the important issues.

In October, 1986, the ARC joined with several other national organizations which were members of the Consortium for Citizens with Developmental Disabilities (CCDD) and embarked on a several-month long process to determine whether there now could be agreement about the basic principles which should be incorporated into Medicaid reform. The organizations represented parents,and consumers, advocates, professionals, providers, and state directors of programs for persons with mental retardation and developmental disabilities. Along with the ARC, they were: the American Association on Mental Retardation, the National Association of Developmental Disabilities Councils, the National Association of Protection and Advocacy Systems, the National Association of State Mental Retardation Program Directors, The Association for Persons with Severe Handicaps, and United Cerebral Palsy Associations, Inc. Months of work resulted in the document "Tentative Specifications: Developmental Disabilities Medicaid Reform Legislation" to which each of the organizations subscribed, with the exception of TASH (which felt that the document did not go far enough toward achieving the overall TASH goal of calling for the closure of institutions).

Since the development of a document of basic principles, this working group has been joined by: the Autism Society of America, the

Epilepsy Foundation of America, the National Head Injury Foundation, and the National Association of Private Residential Resources. With a basic set of agreed upon principles in hand, the participating organizations then began to work with the offices of Senators John Chafee and Lowell Weicker and Representative James Florio to develop a bill which could incorporate the basic principles agreed upon for reform of Medicaid's long term care program. The resulting bills, S. 1673 and H.R. 3454, are the result of months of intense work by the participating organizations and Congressional offices. They reflect a concerted attempt to respond to past criticisms of the CFLA bills and to reach a workable middle ground where reform would be achievable from the viewpoints of each of the various organizations involved. Thus, ARC views the "Medicaid Home and Community Quality Services Act of 1987" as a true compromise which reflects the Medicaid reform interests as well as the practical concerns of parents, consumers, advocates, professionals, providers, and state agencies.

III. NATIONWIDE WAITING LISTS

The ARC comes to its support of S. 1673 from many perspectives. One of the major reasons for its concern that Medicaid long term care services should undergo major reform is the issue of waiting lists. Throughout the United States, individuals and families are on waiting lists for services in their home communities. These services may be day programs for adults with developmental disabilities, vocational training programs, respite care and other family support services, special transportation services, attendant care, and many other services which make it possible for the individual to remain living with his/her own family, in his/her own home, or in another community-based residential setting. The availability of these individual or family support services is the real key to whether an individual can remain at home or whether the family has no alternative but to choose a 24-hour, out-of-home, residential facility placement.

To get a better assessment of the number of people on waiting lists for services to persons with mental retardation, the ARC conducted a nationwide telephone survey. The results of the survey were published in October, 1987 and entitled, "A National Status Report on Waiting Lists of People with Mental Retardation for Community Services."

The survey focused on needs in two broad areas: day services and residential services. Information was collected from state ARC chapter directors or, where necessary, other state level advocacy organizations or the state mental retardation program. Figures for residential waiting lists included people waiting for a variety of types of community residences such as group homes, foster homes, or supervised apartments. Figures for day program waiting lists included people waiting for adult day activity programs, vocational programs, early intervention and pre-school programs.

Results of the survey indicate that over 63,000 people with mental retardation are waiting for residential services, while over 76,000 are waiting for day programs. The total of both residential and day program waiting lists is 139,673. (A chart showing results by state is attached as Appendix A.)

The data from this survey should be interpreted cautiously for a number of reasons, including:

- The total of 139,673 is a count of individual service needs rather than people, because some individuals are waiting for both day and residential services and are, therefore, counted twice.
- Data was collected by the states in a variety of ways, and few felt that they had identified all of the people with service needs.

In addition, it is believed that a waiting list survey such as this greatly underestimates unmet service needs. Families who know that certain services are not available may not contact the service system and therefore are not counted as waiting for services. In some states, people are not counted as waiting for a service until they have had a comprehensive evaluation. This service may have a waiting list also; therefore, people wait to wait. In some states, for a variety of reasons (such as cause for litigation against the state), waiting lists are not kept officially.

Even given the limitations of such a survey, the results point to a real crisis in service provision across the country. Furthermore, the results indicate unmet needs of today and do not begin to reflect future needs. Following are a few illustrations of the types of situations calling for immediate action:

- There are thousands of young people leaving special education programs each year (approximately 62,000 with mental retardation in 1985). Many will have needs for residential and vocational services to help them live and work in the community as independently as possible.
- Adults with mental retardation currently living at home with elderly parents will need residential and other services. ARC/Indiana estimates that there are over 2,000 such adults whose parents are over 61 years old. In an extensive effort in Maryland to identify people living at home with families, it was found that 25 percent of caregivers of adults with mental retardation living at home were over 65.
- When families with a young adult with mental retardation leaving the school system cannot find appropriate day programs or vocational services, one wage earner may have to quit working to become a daytime caretaker for the family member.
- Families that cannot obtain in-home family and individual support services are often forced to choose out-of-home, 24-hour residential services as the only means of obtaining assistance for a family member with mental retardation.

The ARC is vitally interested in ensuring that this nation becomes capable of meeting the needs of individuals who wish to remain in their home communities with or near their families. The all-or-nothing choice of 24-hour facility-based care, upon which the Medicaid long term care approach is based, is hopelessly outdated and can never begin to meet people's real needs in a cost effective manner. Even though the Medicaid program is an entitlement program, the facility-based approach leaves many Medicaid eligible people without needed long term care services. The goals of fostering and promoting individual independence, productivity, and community integration which form the basis of other critical federal policy (example: special education and vocational rehabilitation) must become reflected in Medicaid long term care policy as well.

IV. MEDICAID REFORM THROUGH S.1673

The "Medicaid Home and Community Quality Services Act of 1987" would amend the Title XIX Medicaid program to allow the states the flexibility necessary to provide appropriate individual and family support services to persons with developmental disabilities who live with their families, in their own homes, or in community-based, integrated, family-scale environments. The bill would remove the institutional bias from the current Medicaid long term care program and would incorporate the principles of independence, productivity, and integration into federal Medicaid long term care policy. The bill would recognize a high priority for the involvement of individuals and parents in decision making regarding their needs and would, for the first time, provide parents and families a real choice in service settings.

The ARC supports the way in which the bill would structure Medicaid service provision: requiring extensive long term state planning on an annual basis with public involvement in the process. The states' establishment of service standards, based on principles set forth in the bill, will provide the states with flexibility to meet local concerns while avoiding the problems in federal-level standard setting seen in the ICF/MR program (i.e., out-dated regulations; excessive delay in revisions of regulations; a heavily structured, non-flexible model of care). At the same time, the Secretary of Health and Human Services would have the authority and responsibility necessary to monitor the states' implementation of the requirements of the bill.

ARC supports the requirement that case management be independent of service providers and that states be required to show the organizational independence and the lack of conflict of interest of the case management system. Since individual and family support services under the bill are designed to permit individually tailored packages of service rather than facility-based models, the case management system will serve as the backbone of the service system for individuals and families. The case management system will also be an important source of information for state planning purposes regarding the availability of services, gaps or flaws in the service system, and the needs of un-served or under-served persons. With these systemic responsibilities, the independence of the case management system is an important factor.

ARC is vitally concerned with the quality of services provided in any setting. S. 1673 has significant requirements for both the federal government and the states regarding the assurance of quality in the services funded through Medicaid. Opponents of S. 1673 have raised concerns about the ability of states to provide quality services in facilities serving over 15 persons after the freeze on federal funds to those settings goes into effect. ARC believes that the availability of the current level of federal funding to those settings, in conjunction with the states' new flexibility to serve persons in community settings, will ensure that enough funding is available to maintain or improve the quality of care for persons who remain living in the larger settings. From 1977 through 1986, the numbers of people living in institutional settings declined by a third, from 149,176 to 100,421 persons. Given this rate of decline and a recognized reduction in the rate of admissions to institutions, we believe that states will be able to maintain federal standards in these facilities. ARC would continue to maintain its vigilance of the quality of care provided in any and all settings.

V. CONCLUSION

The ARC appreciates the Finance Committee's willingness to address the "Medicaid Home and Community Quality Services Act." We urge you to resolve any outstanding issues and work to ensure passage of the bill in the 100th Congress. The needs for services are clear. The issues have been thoroughly debated and the bill has evolved over the course of three Congresses. To fail to act only prolongs the difficulties of families throughout the country who are desperately seeking services and will result in the continued unnecessary and inappropriate use of 24-hour facilities by families with no other alternative. ARC believes that S. 1673 will, for the first time, offer individuals and families a real choice in Medicaid services to meet their needs.

ARC recognizes the need to address outstanding concerns and remains ready and willing to assist the Finance Committee in reaching solutions and making improvements to the bill. We appreciate this opportunity to submit this testimony for your consideration.

APPENDIX A

NUMBERS OF SERVICES NEEDED BY INDIVIDUALS WITH MENTAL RETARDATION

STATE	RESIDENTIAL SERVICES	DAY PROGRAMS	POPULATION
Alabama	706	1,865	4,079,800
Alaska	14	133	537,800
Arizona	356	1,066	3,252,200
Arkansas	302	523	2,401,600
California		DATA NOT COLLECTED	26,345,300
Colorado	1,050	909	3,269,700
Connecticut	300		3,175,900
District of Columbia		DATA NOT COLLECTED	621,000
Delaware	65	32	621,400
Florida	1,145	2,667	11,435,200
Georgia	1,023	850	5,990,500
Hawaii	350	250	1,071,300
Idaho	Unk.	130	1,029,900
Illinois	10,000	3,000	11,640,400
Indiana	2,000	2,990	5,585,800
Iowa	2,000	1,700	2,942,800
Kansas	643	835	2,470,500
Kentucky	328	655	3,786,200
Louisiana	1,912	939	4,532,600
Maine	1,056	928	1,175,400
Maryland	1,826	2,515	4,436,400
Massachusetts	1,875	1,123	5,847,400
Michigan	2,000	1,900	9,211,900
Minnesota	735	1,272	4,224,300
Mississippi	105	615	2,647,300
Missouri	1,807	Unk.	5,093,800
Montana	426	342	836,700
Nebraska	281	252	1,622,400
Nevada	113	40	940,900
New Hampshire	100	196	1,000,700
New Jersey	1,120	Unk.	7,618,900
New Mexico	310	426	1,475,700
New York	12,394	6,197	17,966,200
N. Carolina	2,180	4,178	6,304,900
N. Dakota		DATA NOT COLLECTED	699,900
Ohio	6,400	5,000	10,836,000
Oklahoma		DATA NOT COLLECTED	3,356,000
Oregon	1,000	700	2,709,200
Pennsylvania	861	3,402	12,012,000
Rhode Island	80	-	969,500
S. Carolina	296	604	3,396,300
S. Dakota	47	47	719,300
Tennessee	725	2,000	4,793,200
Texas	1,900	20,000 (All Services)	16,408,700
Utah	278	324	1,698,800
Vermont		DATA NOT COLLECTED	537,800
Virginia	1,602	1,673	5,785,000
Washington	970	2,747	4,416,700
West Virginia	65	65	1,967,900
Wisconsin	822	949	4,818,000
Wyoming	66 (Day or Residential or Both)		516,400
TOTAL	63,634	76,039	

AMERICAN FEDERATION OF STATE, COUNTY AND MUNICIPAL EMPLOYEES

BEFORE THE

HEALTH SUBCOMMITTEE
COMMITTEE ON FINANCE
UNITED STATES SENATE

S.1673: MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT

MARCH 22, 1988

Good morning. I am Jerry D. Klepner, Director of Legislation of the American Federation of State, County and Municipal Employees.

I am speaking today on behalf of 100,000 AFSCME-represented workers who care for the developmentally disabled.

Since the Community and Family Living Amendments were first introduced in 1983 our union has opposed this type of legislation. We have not been alone. Last session, over 120 different parent, consumer, worker, and provider groups also opposed the bill.

Our position has not changed. We believe the latest draft of the Medicaid Home and Community Quality Services Act remains a massive contracting-out scheme detrimental to both residents and the individuals who care for them. Our union is not opposed to Medicaid ICF/MR reform, but we believe such change must be developed in a thoughtful, responsible manner.

Dramatic cost increases in the ICF/MR program over the past five years have forced federal and state administrators to reconsider the overall mission of the Medicaid program for the developmentally disabled. The rising federal budget deficit will guarantee continuing scrutiny of domestic social service programs which have incurred increased costs.

As a union of members who care for the developmentally disabled, we have experienced firsthand the consequences of escalating Medicaid costs. For example, when ICF/MR facilities have lost their Medicaid certification due to "active-treatment" deficiencies, state administrators have willingly forfeited Medicaid funding rather than accept the difficult task of providing quality care. Cleveland Developmental Center outside of Cleveland, Ohio, and Pueblo Regional Center in Pueblo, Colorado, immediately come to mind as examples. In both of these instances, the states have closed the facilities and have transferred the residents to other ICFs/MR, thereby creating larger, crowded institutions far from the resident's relatives.

Though costs are an important aspect of the debate regarding the provision of care for the developmentally disabled, the focus of Medicaid reform should be primarily upon the quality of care and treatment provided these individuals. For the following reasons, we believe the Medicaid Home and Community Quality Services Act fails to insure that quality services will be available to all developmentally disabled individuals in the community.

Flaws in the S.1673 Conceptual Framework

First, S.1673 arbitrarily limits facility size to at most nine individuals and, possibly, as few as six. Neither research nor experience indicates that the least restrictive environment for all developmentally disabled individuals is in a small community group home. Certainly, many disabled individuals may benefit from community life but, for others, the least restrictive environment may be a 10, 30 or 300 bed facility.

This point reminds me of a recent attempt by the Washington State Department of Human Services to phasedown Interlake School in Medical Lake, Washington. Of the 232 residents living at

Interlake at the time, 229 individuals were profoundly retarded and 153 had two or more handicapping conditions in addition to their retardation. All of the residents had at least one additional physical handicap. Two individuals of the 232 were ambulatory. In addition, at least 40 residents were described as having medically intensive needs. Certainly a newer and more spacious facility might better meet the needs of Interlake residents. It is doubtful, however, that the majority of these individuals could ever live safely in a small community group home.

Secondly, the Medicaid Home and Community Quality Services Act both directly and indirectly creates incentives to close existing ICF/MR facilities. S.1673 directly caps the payments for services provided in large facilities to the state under Medicaid. In other words, current federal ICF/MR Medicaid funding would be frozen at a base year level. As inflationary and active treatment demands drove up costs, states would only be able to draw from a fixed pot of Medicaid funding. At the same time, additional funding would be allocated to community services. Given such a windfall, state officials could not resist using their new community funding to purchase more services that are less expensive, rather than ensuring that more costly needs are met.

Furthermore, it is unclear whether S.1673 permits Medicaid payments to be used to correct deficiencies cited during the ICF/MR survey process. In fact, the Medicaid Home and Community Quality Services Act would grant greater flexibility to states which opted to close or phasedown facilities. Specifically, states would be encouraged to close large ICFs/MR over a 36 month period to avoid incurring increased institutional staffing and physical plant improvement costs. Such an anti-institutional bias denies the need for a unified continuum of care.

Large public ICF/MR facilities, as centers of research, as emergency centers and as repositories of skilled/experienced human resources, provide a vital link in the overall service delivery system to the developmentally disabled. Simply shifting Medicaid funds from institutional to community services does not guarantee delivery of quality continuity of care.

A third inherent flaw in the bill concerns those provisions that would allow a state to establish its own rules and regulations to monitor the quality of newly established community services. Federal ICF/MR regulations, many of which relate to staffing and programming and are vital to quality care, would no longer apply. Instead of standardized federal regulations, which are themselves too frequently misapplied, S.1673 would promote a patchwork pattern of standards which would mirror state interest and funding but would not necessarily meet the needs of residents.

Shifting current Medicaid funding without providing accompanying unified standards would only exacerbate the inadequacies of the current community service delivery system across the country. We are confronted with the failure of that community system every day. A Cleveland Plain Dealer headline in November, 1987 entitled, "Ohio's Severely Retarded Still Trapped In Misery" along with numerous other newspaper articles from around the country testify to the ongoing tragedy.(1) In Ohio alone, over 6,000 mentally retarded individuals are on waiting lists for community housing. For many of these individuals institutionalization is nearly impossible and parents are reluctant to abandon their offspring into inadequate community facilities.

If half of all residents who currently live in public ICFs/MR were moved to the community in the manner outlined in S.1673, between 12,000 and 18,000 new group homes would have to be added to the current community system. Without uniform regulations, we are concerned that the states would simply continue to inadequately monitor community staffing levels and programming needs.

A fourth concern with S.1673 focuses upon parental concerns. A recent national survey of families of institutionalized persons with mental retardation concerning attitudes towards deinstitutionalization reveals that 88% of the respondents reported that public ICFs/MR provided the types of services and care that were needed by their relative with mental retardation.(2) The general issues of most concern to the respondents were security and 24-hour supervision for their relative. Sixty percent of the respondents expressed concern over whether such matters could be adequately addressed by community providers.

Overall, the role of parents in the written habilitation plan determination process of S.1673 is minimized while great emphasis is placed on professional consultation. Similarly, parents or relatives have no real decision-making power over whether an individual is transferred from a large ICF/MR to a community setting. The current "reform" bill does permit a transfer appeals process but the expense of legal relief would prevent many families from pursuing it. Relatives could be arbitrarily moved to a setting far from parental guardians, and opposed by them.

Fifth, the Medicaid Home and Community Quality Services Act minimizes the role of skilled, experienced human resources in the overall service delivery system. Under S.1673, training or retraining would be provided for displaced workers but only after displacement. The proposed legislation provides no mechanism for redeploying highly skilled workers into any new community system. In essence, like residents dumped into inadequate community settings, workers would be dumped into an existing poorly trained community workforce.

A February, 1988 wage and benefit survey completed for the Association of Residential Resources in Minnesota and the

Minnesota Developmental Achievement Centers Association by ROI Consultants found that the costs of recruitment and training within community-based development and treatment facilities was significantly higher than those borne by schools, counties, and private employees. This outcome was due in part to higher than usual levels of turnover.

In positions paying less than $6.00 an hour, the turnover averaged 67.5% annually.(3) In the least desirable positions (live-in-counselors and night- attendants) the turnover was reported by some agencies to be as high as 200% annually. According to one developmental disability specialist, a reliable, steady nucleus of aides is important because they "understand residents' behavior, react better to difficult situations, and are not as easily provoked by angry residents."(4) In other words, emphasis should be placed on staff retention and improvement regardless of the workplace, institutional or community, rather than on constant recruitment and replacement.

Moreover, unlike federal ICF/MR regulations, S.1673 contains no staffing ratio requirements. The proposed legislation would simply maintain the existing inadequate community system of staffing instead of enforcing uniform minimum standards. Without staffing and equitable compensation mandates, S.1673 would guarantee minimum care and unacceptable staff turnover.

An AFSCME Alternative

As national experts and officials in one locality after another have looked at the results of deinstitutionalization, they have identified a common set of problems. First, there are inadequate numbers of community-based services. Second, state facilities are overcrowded and understaffed. Third, no one is accountable for those needing community-based services. Finally, states have inadequate quality and price control over community-based services.

Our union rejects the idea that these problems are merely the result of spending too much on state facilities for the developmentally disabled. One of the critical concerns nationwide is that private community-based providers cannot or will not treat persons with severe or profound developmental disabilities, the persons for whom the state has historically cared. This problem will be compounded by the new requirements contained in the Nursing Home Reform Act of 1987 which mandates active treatment for developmenttal disabled individuals residing in nursing homes. Nursing home operators will be forced to choose between conversion to ICF/MR status and moving residents out of their nursing homes and into alternative, currently non-existant, community settings.

Instead of making arbitrary changes in funding systems for the developmentally disabled, states like Arizona, Colorado, Connecticut, Florida, Kansas, Louisiana, Massachusetts, Mississippi, New Jersey, New York, Oklahoma, Rhode Island and South Carolina have made a commitment to provide a state-operated continuum of care, that includes institutional, community residential and, in some instances, day treatment services. These states have found that the availability of publicly-operated community-based services eliminates major service delivery gaps.

Massachusetts, Minnesota, and Rhode Island make good case studies of the process of shifting resources.

In 1980, the Massachusetts Taxpayer's Foundation published a study of the state's purchase of service system. The study concluded that the state had lost control over the system. Because Massachusetts was not prepared to provide community-based services to persons with developmental disabilities, the state became completely dependent upon and at the mercy of private providers. The state was not in a position to require reforms from the providers, nor to resist their demands for more money. After numerous crises, Massachusetts chose to directly provide care to the disabled in the community. As of 1980, sixty percent of new community-based facilities for developmentally disabled persons are state-owned and operated.

The State of Minnesota has extensively used the ICF/MR program to develop community-based services, but few severely disabled individuals have been moved to private sector ICFs/MR. Eighty-five percent of those individuals remaining in the state's regional centers are severely or profoundly disabled. Through the use of a Federal Mediation and Conciliation Service grant, which established statewide labor-management committees, AFSCME and the Minnesota Department of Human Services undertook joint labor-management planning for the development of state-operated community facilities. To date, eight state-operated homes, with four residents in each home, have opened in the communities of Cambridge and Faribeault. State workers from nearby regional centers have been retrained and now work full-time in the state-operated community facilities. In future legislation, our Minnesota Council hopes to expand upon this promising state-operated continuum of care.

In Senator John Chafee's home state, AFSCME Council 94 and the State of Rhode Island signed an historic agreement in 1979 which set forth the first comprehensive state-operated continuum of care. That agreement emphasized placement in the least restrictive environment for residents and transfer without layoffs for workers. A decade later over 150 residents live in small state-operated groups homes and HUD-supported apartments.

Any Medicaid reform measure must emphasize the use of current human resources within a state-operated continuum of care. Following the example set by Massachusetts, Minnesota and Rhode Island, states should recognize the value in upgrading existing ICFs/MR while establishing state-operated community facilities for developmentally disabled persons.

State operation in the community will insure access to care, accountability, and continuity of care. Parents and relatives of the disabled support the emphasis in such a plan on permanence and constant supervision. Higher staffing ratios and lower worker turnover should similarly be embraced by state administrators and advocates.

There is no question the current service delivery system for the developmentally disabled, at both the institutional and community levels, can be improved. But we believe the Medicaid Home and Community Quality Services Act is not the vehicle. Developmentally disabled individuals have experienced the effects of radical deinstitutionalization in the past. We must not allow such treatment to be endured again. We believe state operation of a full continuum will allow residents to receive quality care in the least restrictive environment and will meet the unique needs of this country's most vulnerable population.

Our members are eager to address the challenge of providing quality care to the developmentally disabled in the future. Through state operation of institutional and community services, we believe, the developmentally disabled will be guaranteed the care they so urgently need and deserve.

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(1) "Leaving Springfield: The Legacy of Deinstitutionalization," Washington Post May 12-14, 1985. "Victims of Change: The Retarded" Cincinnati Enquirer, September 30, 1984, October 1-3, 1984; "Retarded-Care Group's Service Topic of Inquiry," Des Moines Register January 6, 1988.

(2) S. Spreatt, et.al., "Attitudes Toward Deinstitutionalization: National Survey of Families of Institutionalized Persons with Mental Retardation," Mental Retardation, October, 1987 Vol 25, No.5, p.270.

(3) ROI Consultants, "Preliminary Wage and Benefit Survey," February 5, 1988, p.6.

(4) "Annual Staff Turnover of 70% Plagues Va. Facility For Mentally Retarded," Washington Post, February 16, 1988.

by

J. Gary Mattson

NATIONAL ASSOCIATION OF PRIVATE RESIDENTIAL RESOURCES
STATEMENT OF TESTIMONY ON
THE MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT

The National Association of Private Residential Resources (NAPRR) is pleased to have an opportunity to testify before this Subcommittee to present the views of Association members regarding the Medicaid Home and Community Quality Services Act of 1987 (S.1673). Our Association currently represents more than 650 agencies in 49 states and the District of Columbia. Together these providers serve more than 40,000 people with mental retardation and other developmental disabilities. Almost 20% of NAPRR members serve just 6 or fewer people, 24% serve 7 to 16, 31% serve 17 to 50, 15% serve 51 to 100, and just 10% serve more than 100 people. Most NAPRR members serve people at more than one site. Several of those who serve more than 100 people do so entirely in small, community settings. Last year almost half of our members provided us with more specific data regarding the numbers of homes they operate and the number of persons served in those homes. At that time, 295 agencies were serving 18,603 individuals at 1,684 sites; or an average of 11 people per site.

No one will dispute the fact that the trend in residential services for more than a decade has been to serve people in smaller and smaller community based settings. In April 1987, the NAPRR Board of Directors met to discuss the values that should underlie the development and provision of residential settings nationwide. The statement they released defining the "Optimal Residential Environment" appears as an Appendix. It reflects the NAPRR position that funding should support people in individualized community settings that, among other things, encourage privacy and opportunity for choice, with a rhythm of life similar to that experienced by the community as a whole. NAPRR therefore strongly supports modification of the Medicaid program by, to use Senator Chafee's words, "changing it from a program that demands dependency to one that seeks to encourage personal growth and is tailored to the needs of each individual with a disability." We also support his statement that: ". . . services for those with disabilities should be available in a variety of residential settings." Achievement of these goals will require careful, long-term planning of the kind outlined in S.1673, but with additional features.

Since other witnesses will be focusing on provisions of the bill that apply to the rights and treatment of individuals, in the minimal space allowed, the National Association of Private Residential Resources will focus on the application of the bill to private service providers. NAPRR is supportive of the many provisions of S.1673 which are critical to assure that both the people now receiving services, and those who will access services as a result of these Medicaid amendments, will receive all services necessary to maximize their growth and development. These include:

- The expansion of the Medicaid program to provide services for more people, with different levels of need, in a variety of family and community living arrangements;

- The provision that will gradually expand eligibility for services by increasing the age of onset by one year each year after enactment, thus providing more adequate funding for many already served by NAPRR members;

- The mandate that services be provided in accordance with each individual's written habilitation plan, which will be developed with the involvement of the person, his or her family, and others, as appropriate;

- The mandate that the state implementation strategy set forth specific objectives and a projected schedule "for transferring individuals . . . to more appropriate residential settings." This will give individuals served, their parents and guardians, providers and others an opportunity to comment on the adequacy and appropriateness of the state's plan, including the allocation of resources;

- The provision under the state's implementation strategy that would mandate protection of people who remain in a larger setting, should it be determined that they would be better served in a family or community living arrangement. Providers fear that privately-operated ICFs/MR may be decertified or that funding to other large private facilities will be reduced. The importance of this provision cannot be over-emphasized. States must not be permitted to reduce the level of services provided in any facility by decertifying it and funding services at a custodial level of care;

- The mandate that transfers be made with the involvement of the individual and, as appropriate, others; and "only to a facility or program that is capable of providing an appropriate array of community and family support services . . . consistent with such individual's written habilitation plan." It is important that state implementation decisions reflect a reasonable prioritization of transfers, with those in greatest need transferred first, as consideration is given to personal choice, the quality of services and the relative degree of community integration experienced by the people who live in larger settings;

- The requirement for public participation in development of the State Implementation Plan, particularly regarding the distribution, period for comment and opportunity for hearings;
- The opportunity for a provider to appeal a deficiency identified during the required assessment of the quality of services, and to receive training and technical assistance to eliminate the deficiency;
- The right of an individual to choose among available licensed or certified providers of services, and the right to a fair hearing;
- Fair employment standards and equitable compensation for workers in private agencies. We cannot give enough emphasis to the importantance of this provision. Reimbursement rates in most states result in a wide discrepancy between employee salaries in the private sector and the public sector. State reimbursement rates do not permit private providers to pay employees salaries and benefits that are as high as those in the public sector. Parity is a must!

Concerns of the National Association of Private Residential Resources focus in the following areas:

- Community living facility definition -- this, with the proposed freeze in funding for larger facilities, is the most controversial part of the bill. NAPRR members have been unable to reach consensus regarding an appropriate definition. Since phase-down of larger settings is no longer mandated, we will not recommend a change in the definition except to suggest that consideration be given to the configuration of apartments, particularly large highrise buildings or garden apartment complexes where several apartments could be utilized by people with disabilities without destroying the concept of integration.

NAPRR also recommends that apartment buildings, such as those developed under the Section 202 program of the Department of Housing and Urban Development of up to twenty-four units, be grandfathered into the community living funding stream. Likewise, clusters of more than two homes, each serving up to 15 people, should be grandfathered in if they are otherwise integrated into residential neighborhoods.

Provisions should also be made for people to receive Medicaid assistance if they live on small family farms. Farm life is the norm in many parts of the nation and will be the environment of choice for many people with mental retardation. Special care must be taken to assure that people participate in community activities, but this is as true in urban and suburban areas as in rural areas. People can be isolated and neglected in any setting, including one's own family home.

- Case management services — NAPRR supports the requirement that a case manager be free from a conflict of interest with respect to the provider of services. We fail to see, however, how this can be possible if a state agency serves in the capacity of case manager while the state also continues to fund, regulate and provide services, including (in many situations) guardianship services. Case managers should be advocates for clients, accessing and monitoring services. When the state assumes this role, there is sometimes a tendency to act as a gatekeeper, accessing services based on cost and availability rather than need.

Minimum criteria for the "qualified" individuals who provide case management services should probably also be included in statutory language to assure that they at least meet requirements of qualified mental retardation professionals as defined in proposed ICF/MR rules.

The role of this individual is also somewhat unclear. Is the case manager a part of the interdisciplinary team, and what is his or her role of authority in the decision-making process? Can the individual or others involved in the IPP process overrule decisions of the case manager without resorting to the formal appeal process?

The waiver of Medicaid freedom of choice requirements in regard to the selection of a case manager is particularly troublesome and significantly limits an individual's right to control this service in any way. People who are eligible for Medicaid services have the right to choose all other qualified providers, including physicians. It is inconsistent not to permit them to have freedom of choice in the selection or rejection of a case manager. The case management section is of paramount importance to this proposed legislation, but, to use the words of one NAPRR member, "We are betting the ranch on an unknown commodity." We know of no case management system that can serve as a model for this legislation. This section of S. 1673 requires considerable additional thought.

- Employee protections — provisions to protect the rights of public sector employees who are affected by the transfer of individuals to community or family living facilities should be extended to private sector employees as well. While we grant that states cannot make the same guarantees of jobs, salaries and benefits to employees in the private sector, retraining and job recruitment should be provided by the state for private sector employees who lose jobs due to the transfer of those served to family or community living arrangements.

- Protection for owners and operators of Medicaid-certified ICFs/MR that do not meet the definition of a community living facility — if federal policy is to freeze aggregate funding for services provided in larger settings, and to transfer many people to small community based settings, there must be affirmative federal relief for all persons who could be adversely affected by the implementation of this policy.

The freeze and subsequent mandated transfer of people to small settings is certainly a highly controversial provision of the bill. While residential programs must not exist for the purpose of perpetuating facilities, but rather to respond to the needs of the individuals served, it is equally inappropriate to fail to recognize the economic impact that this legislation could have on providers, their staff and the surrounding community. When people are moved to community settings, and new admissions are restricted, costs are not reduced proportionally and eventually it is not economically feasible to remain in operation. Directly or indirectly, S.1673 will thus eventually force the closure of many large facilities.

If funding, even in the aggregate, is to be frozen (in effect reduced as the cost of living continues to rise), then the providers who have developed residential services in response to perceived need as well as to government pleas for help, should be protected. Without planned assistance, facility closure will adversely affect individuals, investors, financers, charitable donors and many others dependent on the continued operation of the facility. Destroying confidence in the service delivery system within the financial, mortgage and lending world can be expected to have an extremely negative effect on new service development.

When federal facilities are closed (e.g. military installations) the federal government has protected the surrounding community through the Federal Real Allocation and Relocation Act. That Act authorizes appropriations to fulfill government commitments, to inject aid for retraining employees, and to recruit and replace employers from other areas of the economy. The State Implementation Plan must identify methods for protecting providers affected by this type of Medicaid reform, and funds must be authorized under S.1673 for allocation to states in accordance with their implementation strategies to protect people associated with large nonprofit and proprietary facilities that are closing.

The most effective way to accomplish this might be to provide an incentive for private providers to voluntarily phase down or phase out their services. It could be included as an amendment to Section 3 of S.1673 as a one-time, time-limited program. Funds would be appropriated to protect the losses incurred by nonprofit and proprietary agencies that discontinue services. To supplement the federal/state reimbursement offered through Medicaid, losses experienced by the proprietary sector could be offset, at least in part, by an amendment to the Internal Revenue Code which would permit the use of tax credits equivalent to those financial losses not reimbursed by the state. Such tax credits could be provided for a limited period after passage of the Act and be available only to providers whose clients are moved from existing facilities to small community based living arrangements. Since the nonprofit sector cannot benefit from tax credits, payments for losses incurred by this sector will have to come entirely through the special Medicaid appropriation. The treatment of designated contributions already received by nonprofit agencies will also require some special consideration. The public, nonprofit and proprietary sectors should all receive equal protection under the Act.

- Transition costs — Another element that is not recognized in S.1673 is the cost associated with the transfer of people from a large facility to many small community living arrangements. A tremendous amount of planning and start-up funding is required. An array of new settings must be identified, purchased or leased, furnished and staffed (with trained employees). Seldom are all residents moved at one time. As stated above, when the population of a facility is reduced, costs are not reduced proportionally. It should be permissible for a state to fund transitional costs under the Medicaid Home and Community Quality Services Act.

- Rate-setting procedures -- At the present time, states need not reimburse services in the private sector at the same level they are reimbursed in publicly-operated facilities. The Boren Amendment (Section 1902(a)(13)(E) of the Social Security Act) has been inadequate to protect the private sector. In many states the cost of services in large state institutions is escalating dramatically while reimbursement of services in the private sector has been inadequate to keep pace with increasing costs, and sometimes does not even permit an agency to comply with regulatory requirements. States should be required to use the same rate-setting formula for all Medicaid-funded services, public and private; and the federal government should review each state's rate-setting plan to assure that it provides equitable reimbursement for all services.

- Quality assurance system -- Integration of the comprehensive monitoring system outlined in the bill will be a real challenge. As we understand it, S.1673 calls for a multi-tiered quality assurance system with (1) licensing and certification, (2) annual independent, third-party evaluation of a cross-section of providers, (3) an annual assessment of consumer satisfaction, and (4) periodic assessments by a body composed of parents/guardians/relatives/neighbors; in addition to monthly visits by the case manager (who also has monitoring responsibilities), and the involvement of a protective intervention agency.

Providers are vulnerable to, and experience conflict with, widely differing critiques and evaluations. They may experience under this system, as they do all too frequently under others, one enforcement official demanding a change that the next official wants changed back; and never shall the twain meet to resolve the conflict. It is clear that regulations will have to be developed further defining the composition and roles of each of these entities, and establishing the ultimate authority in evaluating the quality of services. Prohibitions against federal standards in Section 11(f) must not be construed to mean that the Secretary cannot promulgate rules to implement the quality assurance provisions of the bill. Within such rules, care must also be taken to assure that the individuals conducting the surveys are adequately credentialed and trained and that the monitoring does not become more costly than the provision of community and family based services. Consideration must ultimately be given to what the impact of such an extensive quality assurance mechanism is likely to be in practice.

• Protections for families — While many families who have chosen to keep their severely disabled family members at home are clamoring for funding to enable them to continue to keep the family unit intact, it must be recognized that other families who have placed their children or siblings in a home operated by others will not have the ability to bring the family member home, even with added Medicaid resources. The authority of the state is considerably strengthened by S. 1673, leaving little decision-making to families or private providers. We can envision a state system of state case managers using the priorities established by this bill to force families who are psychologically unwilling or unable to care for their dependent to take him or her back into the family home. Insisting where there is unwillingness could have dire consequences for the individuals with disabilities. Many of those served in private residential programs have suffered abuse in large state institutions; many have also been abused by their own families in their own homes. That is not a situation that should be promoted by this Medicaid reform legislation. Measures must be taken to offer families who are unwilling or unable to care for their dependents to place them in another community setting. Provisions will also have to be made for families that inappropriately insist on keeping a family member at home when the individual him or herself, or an interdisciplinary team, has determined that another placement would be better. Families that appeal a decision of the state system regarding the placement of their family member must also be free from fear of reprisal for challenging the system.

As stated at the beginning of this testimony, members of the National Association of Private Residential Resources are strongly supportive of Medicaid reform that will provide assistance for people who live at home or in small community settings. They have reservations about some of the methods proposed in the Medicaid Home and Community Quality Services Act to achieve this goal. The approach proposed by Senator Chafee in 1983 has been significantly modified. We assume that more modifications that will improve it still further will occur before S.1673 is signed into law as a vehicle for assuring that Americans with disabilities are offered every possible opportunity to take their rightful place in society. Private providers are concerned about this bill because they expect to play a major role in its implementation, and they want to be certain that it will work smoothly and well.

STATEMENT

RESPECTFULLY SUBMITTED

TO THE

UNITED STATES SENATE

COMMITTEE ON FINANCE

SUBCOMMITTEE ON HEALTH

AT A HEARING ON S.1673

THE MEDICARD HOME AND COMMUNITY

QUALITY SERVICES ACT OF 1987

MARCH 22, 1988

PRESENTED BY

FLOYD SORG
ELIZABETH, PENNSYLVANIA

ON BEHALF OF
UNITED CEREBRAL PALSY ASSOCIATION, INC.

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My name is Floyd Sorg. My wife, my son and I live in our home in Elizabeth, Pennsylvania, outside of Pittsburgh. I am speaking today on behalf of my family, United Cerebral Palsy of Greater Pittsburgh, UCP of Pennsylvania and United Cerebral Palsy Associations, Inc. and the 700,000 children and adults in this country with cerebral palsy.

Our son, Robert, was born twenty-one years ago in December 1966. At the age of 6 months the doctors at children's Hospital told us that Rob had brain damage which caused cerebral palsy, seizures and mental retardation. They told us he would never be able to do anything and urged us to place him in an institution and forget about him. We could not and would not do that then and we do not want to do that to him now; however, if you do not pass the Medicaid Home & Community Quaility Services Act of 1987, we may have no choice but to move Rob to a nursing home for old people or a state institution because that's where most of the medicaid dollars now go.

By the time we learned about UCP in Pittsburgh, Rob was 2 1/2 years old and "rolled up in a ball" because he had received no therapy. Thank God for UCP. He was enrolled in a developmental class to which my wife transported him for a year and a half, 10 miles each day.

He entered school in 1972 and in 1976 began getting the benefits of the special education law the Congress passed in 1975, P.L. 94-142 the Education for All Handicapped Children Act. This law has allowed Rob to go to school, to learn all that he can and has allowed us to have new hopes and dreams for his future adult life in the community as part of society.

He has one more year of school and will finish in June of 1989. This young man, who the doctors said wouldn't do anything, can feed himself, respond to our words and is now doing some assembly line work in his vocational program even though he cannot talk, walk or toilet himself. Last year he got a wonderful new teacher who has purchased an electronic communication device for the schoolroom and Rob is learning how to use it very quickly - but it cost $3,000 and he only gets to use this one at school. We cannot afford one for him to use at home. Rob likes football and loud music like most folks his age.

I am a proud man and we haven't asked for or received much from government assistance for Rob other than his rightful education and his S.S. I. check, but we have some serious financial problems. In 1984, I was laid off after years of work at U.S. Steel. I have not had a steady job since then. my wife has opened a ceramic shop which is open 5 days per week from 10-3 while Rob is in school.

The small amount of help we get from the county base service unit of the Department of Mental Retardation amounts to $500 a year for respite care. We pay $150 for two weeks of summer camp which leaves $350 for respite. At $4/hour for someone who can lift Rob and meet his needs that means 90 hours/year or less than two hours/week! Since he turned eighteen, medicaid pays $95 per month for his diapers and two seizure medications.

That is a total of $1,640 per year. I understand that if Rob went to a nursing home, medicaid would pay about $30,000 a year for his program and if he went to the state school, they would pay as much as $65,000 per year. That is not fair - and it doesn't seem real smart either.

Our extended family, like many today, is not readily available to support us. Our daughter lives in Ohio and has two youngsters of her own. My mother is 70 years old and 5 feet tall. My mother-in-law and sister-in-law live 50 miles away from us. My wife and I are worried about what will happen if, God forbid, one of us becomes very ill or dies . We have had no choice but to look for places for Rob to live. There are no group homes in our area for persons who are not ambulatory - and even if there were the new group homes are primarily for persons coming out to the institution not for people now living at home. The UCP supported apartment project is full and no new funds are available. The two private institutions where we have applied have a waiting list of eight to ten years and the vocational day program has a waiting list of three years.

I don't claim to understand a lot of this legislation and funding, but I do know it doesn't make sense for us to have worked so hard for Rob to live at home and grow up with his family and friends in the community, spend taxpayer dollars for him to go to school and learn how to live and work to his potential if he is then forced to sit at home or go to an institution. He will absolutely disintegrate if he doesn't have the love, support and ongoing stimulation in his life.

United Cerebral Palsy Association, Inc. strongly endorses S.1673. As part of the Consortium for Citizens with Developmental Disabilities and its task force on long term care medicaid reform, we have worked closely with other national organizations and the sponsors of the legislation, Senators Chafee, Weicker and Mitchell, to build consensus on a bill that removes the "institutional bias" of the current medicaid ICF/MR program, eliminates the limitations of the home and community based waiver program, recognizes the direction of all other federal public policy on behalf of people with disabilities enacted by the Congress since 1963, recognizes and mandates the necessary components of a comprehensive, dispersed community service system, and recognizes families as the primary caregivers for children with severe disabilities.

Specifically, we urge you to leave the eligibility intact for person with severe disabilities who are S.S.I. eligible so that we have a truly national eligibility standard as opposed to 50 variations on the theme for the current ICF/MR program.

We urge you to maintain the independence of the case management program. If the people in these positions are to function as advocates and monitor the services they cannot be employed by an agency at the local level that is also responsible for the direct delivery of the residential, vocational, early intervention and other direct services. To permit a direct "conflict of interest" undermines, the true purpose and intent of a system of case management.

One area that we urge you to strengthen in the bill is a formal linkage between the services defined for a person in the

Individualized Habilitation Plan and the rates of payment to private service providers to meet the services goals and objectives for the person. In particular, the rates must recognize the specialized and intense support services for individuals who are disabled as a result of severe physical impairment, sensory impairments and multiple impairments rather than continuing to provide these specialized services on a pure mental retardation program design an rate system.

Moreover, the state's five year implementation strategy should include additional language to assure a rate setting mechanism which is consistently applied to both public and private providers that is based on valid and appropriate indices including cost of living increases, minimum and prevailing wages with a health benefit package for all staff, provides adequate funding for all staff, provides adequate funding to cover all fixed costs of operation (e.g., liability insurance, workers compensation insurance, etc.) and all other costs required to provide quality community and family support services. The rate setting mechanism should be based on the actual cost of providing services and the number of medicaid participants receiving services.

Once additional component we suggest be added to the bill regards the reimbursement for the closing of large facilities which recognize the costs of transition services for acquiring, moving in, operating and properly staffing a community living facility and to cover the operational costs of the larger facility from which individual are moving during the "phase-down/phase out" period.

This landmark legislation has been developed over the past five years and needs to be enacted in 1988. Continuing the current medicaid program as an institution model is unconscionable in this day and age. We urge you to act now to redirect the future of medicaid funding to family home and community living so that my son and all children and adults with cerebral palsy and other severe disabilities can realize the American Dream as you the Congress have defined it in the Developmental Disabilities Assistance Bill of Rights Act to assure increased independence, productivity and community integration for each person with a severe disability. Then perhaps we will be able to look at the glorious red, white, and blue and truly say that this is a country where there is liberty and social justice for all citizens.

Testimony of

The National Head Injury Foundation

Medicaid Home and Community Quality Services Act

Presented by

Alice Demichelis,
Board of Directors
National Head Injury Foundation

March 22, 1988

My name is Alice Demichelis. I am a member of the National Head Injury Foundation's Board of Directors and a full-time volunteer for NHIF. I live in Reston, Virginia. I want to take this opportunity to thank the committee for inviting me to testify on behalf of the National Head Injury Foundation, regarding the importance of the "Medicaid Home and Community Quality Services Act".

National Head Injury Foundation has 18,000 members, 31 state associations and 7 affiliate chapters. We have 350 support groups nationally. We are a non-profit agency supported by membership dues, fund raising events, contributions and grants. Our membership is composed of families, friends, medical and social service professionals concerned with the well being of persons with a head injury.

Today, I am appearing here in the capacity of a mother of a son who sustained a closed head injury in a single car accident in February 1980. The accident occurred in Chicago, Illinois. He sustained lower brain stem and frontal lobe damage. He has no physical disabilities. At the time of his accident, Robert was 23 years old and just beginning his career as a CPA for one of the "Big Eight" accounting firms. He is now 31 years old.

In 1967, we lost a 9-1/2 year old son, Stephen, to a gun accident. It is very difficult to describe ones feelings when something like this happens in a family. But, I do know that death has a finality. We mourned and we healed. Nothing ever again could be so terrible--until my son Robert's auto accident.

At the time of Robert's accident, I was a director of a small local art gallery. Five months after Robert's accident I had to resign my position. For the first time in our lives, we were rendered helpless and impotent at the mercy of the medical profession, Robert's employer, the insurance industry, and our Federal and State governments, because of their total lack of knowledge of this disability.

Traumatic head injury is an insult to the brain, not of a degenerative or congenital nature, but caused by an external physical force, that may produce a diminished or altered state of consciousness, which results in impairment of cognitive abilities or physical functioning. It can also result in the disturbance of behavioral or emotional functioning. These impairments may be either temporary or permanent and cause partial or total functional disability or psychosocial maladjustment.

According to Epidemology Studies as Reported by NINDCS Head Injury & Stroke Status Report, 1985, head injury or the "Silent Epidemic" accounts for more than half a million hospital admissions per year. 50,000 to 70,000 people a year are permanently disabled. Most people who sustain a head injury are under the age of 30, and most are injured as a result of tragic motor vehicle and sports accidents. Accidents that physically disable and intellectually impair for a lifetime. Under the age of 34, head trauma takes more lives than heart, AIDS, stroke and cancer combined.

Until the establishment of the National Head Injury Foundation, (NHIF) in 1980, no single Federal, State, or private agency concerned itself exclusively with persons with head injury and their families. Until NHIF, this lost population was silently and shamefully closeted away, and inappropriately placed in psychiatric institutions, schools for people with mental retardation, or nursing homes.

Two months after his accident, Robert was ready to be released from intensive care in Chicago to a rehabilitation hospital. I began looking toward the D.C. area for this service. The hospital recommended was George Washington University Hospital. The same hospital where James Brady is currently a client. We air med-vaced Robert to D.C. at our own expense. (His employer's insurance company refused to pay.)

After receiving speech and physical therapy as an inpatient for three weeks, Robert was discharged home and continued receiving speech and physical therapy as an outpatient for two more weeks. The therapies at George Washington University Hospital did nothing to address the personality and cognitive disfunctions that resulted from his brain trauma. Upon his final release from GWU, we were advised to contact a vocational psychologist. Although this psychologist had a very fine reputation, we were very much surprised to learn that the psychologist had no experience or training that would help him in dealing with a CPA's occupational responsibilities.

After four months of visits, twice a week, the psychologist recommended that Robert return to Chicago and resume his job as a public accountant. His doctor gave no warning of what to expect. My husband did counsel his employer not to subject Robert to the same type of case load that he had prior to the accident.

Over the next six months it became apparent to Robert's employer that he was having great difficulty fulfilling his responsibilities. He received psychological counseling after his return to work, but his performance continued to deteriorate, not only on the job but with his personal life.

In August of 1981, his employer unilaterally transferred him to their Washington, D.C. office, and placed him on disability. They strongly recommended that Robert return to our home and resume contact with the medical professionals who had previously treated him. In the meantime both the vocational psychologist and the neurologist had died, and the doctor who had treated Robert in the rehabilitation unit at GWU had retired. I called GWU for recommendations. They did not have any. Thus, began our long road to Hell. In our ignorance and desperate need for help as a family with no training, we began the disastrous road of "brokering" inappropriate services.

The doctors we consulted had never dealt with a Traumatic Brain Injury case. They treated Robert as a psychiatric case, further complicating the issue. None of these doctors informed us of their lack of expertise in the field of head trauma, and we as a family did not have the expertise to ask.

February 1982, Robert's psychiatrist advised him to enter the Psychiatric Institute of Washington, D.C. He was at the Institute for two months where again the treatment was totally inadequate and inappropriate for a person suffering from TBI. The total cost for the two months of care was $25,000, exhausting Robert's psychiatric coverage under his group insurance policy. He was discharged to our home and began a day program at the Northwest Mental Health Satellite located in Reston. Again, another set of doctors with no training in handling persons with head injury. Two weeks after his discharge, a catastrophic personality conflict occurred. I called PI and was told that they would not let Robert return unless we (his parents) came up with another $11,000 up front. The end result was that we had no choice but to commit Robert to the Northern Virginia Mental Health Institute. Again, a new set of doctors, and a new hospital. And again, the treatment was inappropriate for TBI survivors.

After 4 weeks at Northern Virginia Mental Health Institute, he was again discharged home. I asked the social workers to help me find a place that treated people with head trauma and was told "if I find one, call them--they knew of none", and again making my husband and myself untrained case managers.

From 1980 to 1982, about half of Robert's medical bills were covered by his group health insurance through his employer. In March 1983, Robert's disability income was terminated. The insurance company decided that benefits payable due to his inability to perform his "own occupation" had been paid and that he was not eligible for long-term coverage. He was immediately informed that his employment was terminated and that he had the option to convert his group medical insurance coverage, but on a limited basis. He was advised by his employer to apply for SSDI benefits and that when Social Security benefits were awarded, his medical insurance would be reinstated. (Robert previously applied for SSDI benefits in 1981, but was turned down.) Therefore in 1983, we assisted Robert in applying for disability benefits, over his objections, since Robert's brain injury did not permit him to recognize the full extent of his disability, or the consequences of his failure to apply. Because the extent of his disability is not immediately apparent to others, his application was again denied by Social Security and we had no choice other than to hire a lawyer. In the meantime, NHIF was in the process of advocating for a change in the SSDI mental impairment listings to recognize "head injury". Subsequently, Robert's application was re-reviewed and with the help of Marilyn Price Spivack, founder and Executive Director of NHIF and our lawyers, he was awarded SSDI in August 1986--6-1/2 years after the accident.

From 1983, when Robert's insurance benefits had been terminated, to 1986, my husband and I paid all of his medical expenses. The total expenditure was $25,000, exhausting of our savings. At that point, I asked Virginia Department of Rehabilitative Services (VDRS) for help. They granted Robert 20 visits to a speech therapist. That was the full extent of financial aid granted to Robert. Additional efforts at vocational rehabilitation through the Virginia Department of Rehabilitative Services (VDRS) proved to be unsuccessful, and for a very valid reason. Training of vocational rehabilitation counselors under VDRS to deal with TBI Clients did not start until November 1984, 4-1/2 years after Robert's accident. VDRS has since closed Robert's case. Robert's eligibility for Medicaid was finally approved in 1984, but we soon discovered that it did not cover the services or therapies required.

This recitation of costs and lack of services does not reflect the family trauma or other expenses we have incurred following Robert's trauma. Nor do they reflect the very real possibility of my husband and I having to sell our one asset, our home, in case something should happen to one of us in the future. That is a very real fear. Nor do they reflect the costs of the current medical care I am receiving; all stress related.

The frustration of families unable to obtain essential services for their loved one may best be described by an event which occurred in Northern Virginia, three years ago. A mother in our Northern Virginia Head Injury Support Group killed her son and herself after losing a law suit against a helmet manufacturer. All other financial resources had been exhausted. The loss of that law suit was only the tip of the iceberg. We all grieved for the loss and the final act done out of desperation. But I have to tell this Committee, that the unspoken is often spoken among our mothers, not only in Virginia, but across the country.

Today, the majority of our TBI survivors, like Robert, are living at home, desperately in need of services the "Medicaid Home and Community Quality Services Act" will provide. Few states use

Medicaid monies for other than institutionalization. Community based services under current Medicaid waivers do not recognize the needs of head trauma survivors. Furthermore, most medically-oriented models for long-term care of persons with head injury are very costly and inappropriate for people living at home or who could live in small, community based settings.

For example, Medicaid in Virginia pays for inpatient acute rehabilitation without regard to the number of days. They will pay for outpatient care, but the individual must require two therapies in addition to rehab nursing. Only two programs in Virginia are Medicaid approved. These programs are appropriate for the newly injured, because they provide comprehensive services. But those my son calls the "walking wounded", several years post-injury who don't need a full array of services and therapies, or who need a different kind of therapy such as behavioral management, cognitive therapy and work readiness programs, are not eligible for Medicaid assistance.

States currently spend approximately $2.6 billion for community-based services which is not matched by Federal funds. Under this legislation, 75 percent of these funds would be matchable.

Health Care Financing Administration (HCFA) estimates for Fiscal Year 1989 show that 200,000 individuals would be eligible for community-based services under current law. Under the proposed Medicaid Home and Community Quality Services Act, HCFA estimates that 1.4 million individuals -- an increase of 500 percent -- would be eligible for community-based services in Fiscal Year 1989.

Opponents charge that Sen. Chafee's proposal would increase the cost of providing Medicaid through this expansion. However, the cost of Traumatic Brain Injury is presently beyond the means of most Americans.

In conclusion, I want to urge this Committee to support this bill. If it had been enacted into law six years ago, our son Robert would not be a Social Security recipient today. There are many other survivors of traumatic brain injury who have more severe physical disabilities than our son and many of them are lying in nursing homes. Many could be more productive members of their families and society with the availability of home and community services. The bill makes available the exact kinds of services needed by people with Traumatic Brain Injury.

Case Management

Individual and family support services

Specialized vocational services

Habilitation services

Case coordination services

Educational services

Periodic interdisciplinary diagnostic and assessment services

Personal assistance and attendant care

Services to enable an individual to improve or maintain functional capacity

Comprehensive outpatient rehabilitation facility services (CORF)

Crisis intervention

Personal guidance, supervision, counseling and advocacy

Appropriate preventative services, to decrease the needs of a severely impaired individual for future services

Support services to family and care givers, including specialized training and respite care

Few people require all these services, but the availability of individualized community-based services to more people would enable many served inappropriately in nursing homes to live in the community. Furthermore, these services become available immediately after discharge from an acute care facility and to those already at home or in community settings.

One specific feature of this bill is of extreme importance to survivors of head injury. That provision would increase the age of onset by one year each year after the age of 22. Although many people are head injured before age 22 and would benefit immediately, there are many others that become head injured after age 22.

Again, I want to stress the importance of this legislation to the survivors of head injury living in our communities across the nation. They are lonely and insulated within those communities because of the lack of services. They have no friends. Their parents and spouses are the untrained care givers, case managers, friends and social directors. At some point in time, a decision was made to value these lives, but not to value the quality of these lives. Is there life after head injury? The answer could be yes, with the passage of the Medicaid Home and Quality Services Act.

TESTIMONY

BEFORE THE

SENATE COMMITTEE ON FINANCE

SUBCOMMITTEE ON HEALTH

ON

THE MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT OF 1987

RESPECTFULLY SUBMITTED

BY

THE ASSOCIATION FOR PERSONS WITH SEVERE HANDICAPS

WITNESS:

IRENE CARNEY
SPECIAL EDUCATION ADMINISTRATOR
VIRGINIA INSTITUTE ON DEVELOPMENTAL DISABILITIES
RICHMOND, VIRGINIA

TUESDAY, MARCH 22, 1988

Mr. Chairman and Members of the Subcommittee, I appreciate the opportunity to appear before you this morning to discuss the Medicaid Home and Community Quality Services Act. I am here in three capacities: as a TASH member, as a sister of a young woman who died in the institution at the age of 32 even as my father and I desperately tried to move her into the community and as a special education professional who has a strong interest in the future of our children with developmental disabilities. On behalf of TASH I want to thank you for holding these hearings and for the leadership a number of you have provided on this bill. I especially want to thank Senator John Chafee for his longstanding commitment to the redirection of federal funding for the long term care of individuals with developmental disabilities.

The Association for Persons with Severe Handicaps is an organization of almost 7000 parents and professionals who together advocate for community integration for individuals with severe and profound mental retardation. Our members believe that communities are for all people, that individuals with even the most challenging disabilities can and should have the opportunity to go to school, live work and play in their own community. The Medicaid Home and Community Quality Services Act would afford a clear option for such community living to a number of people for the first time. We are supportive of this effort.

However, I must say that our support is not without reservation. When Senator John Chafee first introduced the Community and Family Amendments the legislation mandated the transfer of all long term care Medicaid funding from institutional services to community services within ten years. We very enthusiastically supported this movement toward community living. Organizationally we have struggled with the newer legislation since that time for two major reasons:

o We feel that S. 1673 has compromised the total transfer of funding from institutional services. In reality, the current legislation has the potential of locking a number of people into institutions for a lifetime. People with the most severe disabilities are in the greatest jeopardy of being the residual population, and TASH has grave concerns with this fact.

o We also have serious concerns with the provisions that allow as many as 15 people to live together under this bill as a qualified community living facility. One of the basic premises of this legislation is that people should live in family homes or small family-like homes in the community. The typical family size is close to four people. We do not believe that fifteen people in the same home is an acceptable standard for a small, family-like living arrangement. We would urge this Subcommittee to tighten the provisions to be more reflective of a typical family size.

In spite of our concerns TASH believes this legislation to be a strong first step toward community living. I would like to highlight for you the provisions which we believe are especially important:

o We support the broad definition of people who are eligible for community services. The direct tie to SSI eligibility is the most effective means of reaching the population who are true candidates for community services.

o We support the establishment of strong federal standards for quality care. These provisions were very carefully crafted for the current legislation and we feel they are an essential new ingredient for the success of the services.

o We especially applaud the inclusion of a prohibition of the use of aversive techniques for behavior management. We believe that the right to treatment must be also accompanied with the right to freedom from harm, that quality of services cannot be discussed separate from such protections. The current legislation is very clear on this point. However, it must also more clearly state what is meant by aversive techniques to avoid any misunderstandings that may continue to exist on this issue.

TASH members have been working with prime sponsors of S. 1673 on such a clarification and will continue to provide input when needed.

o We support as one of the stongest and most important pieces of this legislation the freeze on current institutional funding. This is the only mechanism that will really begin to provide new options in a number of states. We urge the Subcommittee to hold fast to this provision.

TASH is committed to total community care for individuals with severe disabilities, and as a first step towards this goal S. 1673 has our support. This support is based on our concern for for the lives of real individuals and what we know is possible for them: our concern for individuals who are now residing in large institutional settings but who could be better served in the community, for individuals who are in the community through the hard work of parents and advocates in their own states to create such options and whose place in the community is continually threatened due to the current funding mechanism, for children who are now living at home because of PL 94-142 but who without comparable federal initiatives for adult services may not be able to remain in the community after they age out of school, and finally, for individuals like my sister, Peggy, who lost the chance to ever experience life in the community.

Peggy was labelled profoundly mentally retarded. She lived at home with my family until 1960 when my mother died and my father was unable to alone care for a family of five children including the special care needs of my sister. She was seven years old when she was placed in the State Institution in Polk, Pennsylvania. There were no other options. It was not until much later as I began my professional studies in this field that I undertook a ten year odyssey to move her home. In spite of attempts at several options we were unsuccessful. We tried everything from a simple institutional transfer which would have at least placed her closer to her home in Pittsburg to our ultimate wish which was to move her into my home where my husband, children and I could have made her a real part of our family. Neither Pennsylvania nor Virginia, where I was then living, had any community resources to provide the support I would have needed in my own home. About the time I began to seek a small, ICF-MR placement she developed a heart condition which, in reality, permanently locked the door to a community placement. There were no ICFs-MR in Pennsylvania for individuals who were medically fragile. I continued the battle to develop such an alternative until her death in 1985.

My family and I carry with us a sadness that she had to die in such a large, impersonal setting and a frustration that the federal system is set up in such a way that no matter how much we wanted to provide her with a home we could not access service money to make it possible. We also carry with us the question as to whether she had to die at such a young age, the question of what her health might have been had she been allowed to grow up and live in a family setting, particularly since the heart condition had gone undetected and then misdiagnosed until our family sought private consultation.

My story is one of many TASH family experiences. I can only share with you a sampling of such stories, and I would like to do so. Let me tell you about Robert Cutler and his Mother, Barbara, who live in Massachusetts. In Barbara Cutler's words:

"Due to the lack of community services I was forced to place my son, Robert, in an institution when he was 24. I could no longer keep him home with me without help and there was no help in the community. I visited him every night and I tried to protect him. I could not protect him from the drugs used in the institution; I could not protect his property; and I could not protect his person. He was beaten regularly by a staff person on the midnight shift. He has no language so he could not tell me of the abuse; I could only know from the bruises and black eyes.

All of this time I was asking for a community placement. I was told they didn't have the right program. When he was turning 29 I realized they would never let him go. And so I started a political campaign to get him out. Within a year he was out. He lives in a small community program, and he is happy. But I constantly fear the shadow of the institution, because without funds for community programs he is still at risk of institutionalization. He can not go back. It would kill him. When I go to visit him now him we have a cup of tea at a real dining room table, we go shopping, we go to the movies. The costs of his community program is very close to the institutional costs, even a little less. Not much less but a little. But what a difference: no more Thorazine, nor more beating, no more loss of personal property. I would like to say the nightmare is over, but it is not until there is good solid community funding."

The Cutler's story very closely parallels that of the Belmontes in Northern Virginia. John Belmonte was beaten in the back room of the institutional ward nightly for one year before the abuse was detected. With no language the only way he could communicate distress was through deteriorating behavior which the day staff, unaware themselves of the abuse, responded to with more medication and restraints. John's parents, Elizabeth and Joe Belmonte, courageously took on a reluctant state bureaucracy and have been successful in securing the first supported living apartment in Virginia. However, the funding is not secure. The Belmontes, too, live under the shadow of the institution.

Finally, let me tell you briefly of Cynthia Schleininger who in all of her 16 years has lived in a number of licensed provider homes in California as well as a large institution because her family was told there were no resources available for them to keep her with them. She can live in a number of small "qualified homes" but she cannot live in her own home.

The families of John, Robert, Peggy and Cynthia are representative of a much larger number of families in and out of

TASH, who upon learning about the real possiblity for their son or daughter, their sister or brother, to live in the community fight hard for such alternatives. These same people are for the most part the same people who were strong supporters of the institutional care in their state until they began to understand that community living was indeed possible for their family member. With the passage of S. 1673 their battles would cease or certainly be made much easier.

Let me make it very clear that TASH does not believe that there is some kind of magic in the community that automatically guarantees quality and safety. As we move away from institutional care in this country we must have in place very strong federal standards for quality of care and human rights, we must have guarantees that all eligible individuals will receive such quality care and we must provide families with the supports they need to guarantee successful services in the community. The legislation championed by a number of you on this Subcommittee provides all of this and more. We in TASH urge you to pass this legislation with all due speed.

Mr. Chairman, I want to again thank you on behalf of the TASH families and professionals for taking the time to hear my statement. I ask that we be given the opportunity to supplement this statement with more detailed comments, including a document being prepared by Addie Comegys, the Chair of the TASH Family Committee and further information on non-aversive behavior management.

Statement of
Patricia Kelly Crawford
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Presented on behalf of the
Mental Retardation Association of Nebraska
before the Senate Finance Committee
Subcommittee on Health
March 22, 1988
Washington, D.C.

Good Morning Senator Mitchell and Committee members and thanks for allowing me to present the reasons for strong opposition to S.1673 by members of the M.R.A.N. We are the parents, families and legal guardians of the most severely disabled Nebraskans, those who reside in institutions.

I am Patricia Kelly Crawford, former president of MRAN and presently Governmental Affairs Chairman. I am a member of the Nebraska Governor's Developmental Disabilities Planning Council since Governor Jim Exon appointed me in 1977 and I have been reappointed by two subsequent governors. My son, Matt, is a resident for 13 years at the Beatrice State Developmental Center, Beatrice, Nebraska.

I wish Matt could be here today and do his own testifying but because he has profound mental deficiency, he has no speech at all. He requires help and guidance for all life activities; eating, bathing, shaving, toileting. He functions, I believe, at about the level of an 18 month old child, yet on Sunday, he will be 27 years old. His needs can only be met in a large facility where he has security, complete and comprehensive and intensive services, training, medical care, and immediate and continuing access to all the disciplines necessary to his care and training.

On one hand, the bill is very generous with the intent of improving and expanding community-based programs. It aims to provide a vast array of services to a vast number of disabled persons. This we applaud and approve - always have - but the bill has a dark side. While it gives to so many, it takes away from the most severely disabled Americans, those who need and rely on your help the most, those who have depended on Medicaid support since 1977.

Nebraska parents strongly oppose S. 1673 because it is a TROJAN HORSE which will close large facilities (over 15 beds) for the mentally retarded. An anti-institution bias pervades the entire bill. S. 1673 caps the Medicaid money received by the state for services for severely disabled individuals. With inflation factored in, the net result will be less money to spend for each person. There will be fewer staff and, a decline in overall quality of care. Large facility residents are the most severely handicapped in the nation, they require the comprehensive and intensive care and the security found only in a large facility. The CPI is now 4% a year. In five years that amounts to a 19.5% reduction; in 10 years, 33.6%; and by year 2000 that will be a 38.8% reduction in Medicaid money for services to individuals. At the same time these institutions must comply with a maze of Federal rules and standards as well as exacting survey teams, or the facility will be decertified: the facility will not be eligible to receive Medicaid funds to render services for disabled individuals.

This bill is a Trojan Horse to close institutions-the "freeze on money to large facilities" attempts to make this effort less likely to attract opposition. The authors of this bill are going through the back door in their Trojan Horse to achieve the ultimate goal - to close institutions. The alternative is to abandon the residents to the capricious, uncertain and finite resources of each state.

This bill also states that if the CPI rises above 6%, payments for persons in large facilities would be increased only to the extent that the CPI exceeded 6%. For example, if the CPI rose to 7%, the payments to those most severely handicapped Americans would only increase by 1%.

The practical effect of this most cruel freeze, this Trojan Horse, would be an actual cut in payments for services to real individual people.

There is a second cruel freeze in this bill - the freeze out of parents and legal guardians from the decision-making teams for our children. We now have the right to participate in planning life activities for our children. If you pass this bill, some bureaucrat will make the decision to include us, "...when appropriate". We are scared and we are outraged.

In a 1980 Touche Ross study of Mental Retardation programs in Nebraska, they found that the main cost factor in providing services was the number of staff who train and care for the disabled folks. This is the reason it costs more to care for the most severely disabled mentally handicapped people who, typically, reside in large facilities which provide comprehensive and intensive services, and the reason it costs less to provide services to the mildly and moderately retarded folks who are often able to ride the city bus and maybe even hold a job.

This bill will require forced removal of persons from large facilities (over 15 beds) to small facilities. Don't be gulled into believing that men like Matt will be cheaper to serve if moved from point A to point B. Their staff needs will not change. A few years ago we had a group home in Lincoln for three very severely disabled girls - one state official referred to it as the Taj Mahal.

If S.1673's Medicaid freeze were to become law, the truly mean and radical cuts in payments for individuals services would cripple the ability of large facilities (over 15 beds) to properly care for the residents. They would have inadequate funds to strictly comply with HCFA standards and rules.

If you believe that old stereotype that these large facilities are warehouses, you are badly misinformed. HCFA allows no warehousing. Each individual has a program plan for each and every hour of each and every day. If this bill is passed, in a few years institutions would not longer be able to meet HCFA rigorous standards, would lose Medicaid certification, and be forced to shut down or depend on less reliable funding sources.

They could even revert back to the snake pits and warehouses of 20 years ago - God forbid.

There are two other provisions that would help to shut down institutions:

1) This legislation would also require the States to set forth specific objectives and a projected schedule over the next five years for transferring severely disabled persons residing in larger institutions to "more appropriate" residential settings.

2) The bill "restricts" admission to any facility larger than 15 beds - this means that any admission would be temporary until a spot in a small facility could be found.

The large facilities operated by Catholics, Lutherans, and other charities will be subject to this law, too, only they will have to make up the deficit with donations, if able.

The wording in the bill, "transferring....persons residing in larger facilities to 'more appropriate' residential settings" clearly reveals the bias against large institutions which pervades this legislation. S.1673 would, as night follows day, result in the elimination of the option of choosing a large facility.

We are so disgusted with the discrimination in this bill against our children just because of their severe handicap. They require comprehensive services and the security of a large facility and for that reason only, S.1673 would ruthlessly cut the Medicaid payments for this most disabled segment of citizens. Can this be consitutional? It is cruel and unfair, at least.

Please kill S.1673. Surely, a bill can be devised that will expand and improve the quality of small facilities without punishing those residents of large facilities by reducing the amount of their Medicaid payments. Remember, this freeze will result in a systematic reduction in Medicaid for a certain segment of disabled persons.

We will always need large facilities for that segment of the disabled population who are multiply handicapped, and have severe or profound retardation.

It is very important that you understand how different the folks are who reside in a large facility. At the Beatrice State Developmental Center, our only state "large facility" (over 15 beds) for the mentally retarded, of the 470 residents, 84% need help bathing, 82% need help dressing, 66% need help toileting, 82% have no speech or are speech impaired. Seventy-three and a half percent have a mental age of near 0-2 years. In addition to mental deficiency, more than a third of the residents have been diagnosed as mentally ill. These figures are typical of large facility residents across the nation.

We, parents and family, support a broad range of services: in-home services, small facilities, and large facilities, so that each individual can be served in the most suitable setting. We cannot support the Medicaid Home and Community Quality Services Act because of the bias against large facilities (over 15 beds) for mentally retarded persons who sorely need comprehensive services.

FINANCE SUBCOMMITTEE HEARING ON S. 1673 MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT

As parents of a beloved 37 year old severely retarded son, who lived in our home 24 years and is now a resident of Oakwood Training Center for the mentally retarded, we would like to submit our views to the Finance Subcommittee as part of the printed record for the hearing on the Chafee Bill S. 1673, "The Medicaid Home and Community Quality Services Act of 1987" to be held on March 22, 1988.

First, we want it understood that we recognize S. 1673 has many good provisions we believe will benefit the high functioning and the mildly retarded with good community living, but we strongly feel the bill DOES NOT REALISTICALLY address the very special needs of the severely/profoundly mentally retarded citizens. It is for this group that we speak and ask that the bias policies discriminating against large institutions with quality care be corrected. When ARC advocates the phasing out of institutions, they do not speak for us or for thousands of other parents across our nation. We do not want community care done at the expense of our loved ones residing in large facilities.

Most individuals at the severe level of retardation need structured 24 hour supervision and care by trained staff for their very survival. This is given only in a large institution and shifting this group into the community will not lessen their special needs on a constant basis nor will it insure normalization for them. A 37 year old man functioning at a 2-3 year old level (like our son) will forever be a child and his mental capabilities will remain unchanged. No matter what S.1673 mandates he will need someone to bath, dress, shave him, supervise his eating, escort him wherever he goes, see that daily medication is given as prescribed and be responsible at all times for his personal well being. This is best carried out by screened, trained staff at the larger facilities with a continuous array of services in place. S. 1673 does not recognize the important necessity for these institutions and we vigorously object to community group homes as the ONLY option in residential care for all the retarded. The Chafee bill as it is now wrriten denies freedom of choice for residents already living in large facilities receiving quality care. This is disastrous for the severely/profoundly retarded segment that we are so concerned about. There must be freedom of choice of a residence that best suits the handicapped individual's special needs. Available options should range from family care to placement in large institutions, depending on the characteristics and abilities of the particular retarded individual and their families. Without this, their constitutional right is jeopardized and their families could be forced to accept dictated care for their loved one that many times is inferior to the care they are already receiving in a large institution. Families do not want bureaucratic professionals to decide where their sons and daughters MUST reside or the quality of care they MUST agree to.

S. 1673 discriminates against larger facilities by proposing a freeze on their Federal funding while there is no such freeze on group community homes. This, ofcourse, will eventually close larger institutions with more than 16 beds. This not only discriminates against the facilities but also against the residents residing there as well. This is grossly unfair and shortsighted.

We object that there has been no input from families of residents living in larger facilities. S. 1673 label "larger" as bad and "small" as good. This is a misguided notion that is simply untrue. As mentioned earlier, our son has been a resident at Oakwood Training Center in Somerset, Kentuc ky for the past 13 years. We stay in close contact with him with regular monthly visits and weekly phone calls and we feel well qualified to tell you that he receives the best possible care with programs that meet his total needs. We do not believe this would be possible for him in community care. Oakwood is a small community in itself designed especially to meet all the needs of the 420 residents there. Our son lives in a lovely homelike cottage with 11 other boys who function at his level of development. He has around the clock supervision and care, training, recreational activities, medical/dental care and the cottage staff are his second family. He is extremely happy in his present environment and enjoys advantages and opportunities that he never had before. As his parents, we feel he is properly placed in his particular least restrictive environment and we would be very upset if S. 1673 forced him into a future community home without the quality of care and programs he now has. Grouping all mentally retarded citizens needs together irrespective of their functioning level and their vast differences makes for unrealistic goals and chaos.

If large facilities are closed, it would result in the "dumping" of thousands of mentally retarded person with no place of residence in dire need of residential care. Forcing institutions to close without regard for their quality and the needs of their residents would simply repeat the disastrous "well meaning" policy that was applied to the mentally ill in the 60's and the 70's. Surely, a lesson was learned from that!

If S. 1673 is passed, the government would have more to say than a parent/guardian regarding their loved one's future. As parents who love their son and are deeply interested in his welfare and are concerned about his future life after we are gone, we object to being lef out with no input regarding his residence and care. We are not at all happy with the idea a Federal statute could restrict the admission or mandate the removal of a retarded person at a facility with 16 or more residents, even though such is required, prescribed and even preferred by the family.

The cost of programs demanded in S. 1673 is not addressed. Studi have been made showing the cost of facility care vs community care is less per resident whenever quality of care and all services are equal.

We have 37 years of dedicated personal experience with our severe retarded son. We were instrumental in establishing a local Center for Handicapped Children. We have worked on behalf of the mentally retard serving on boards and committees, acted as President twice for the Oak Parents Group, working generally for the past 35 years for the retarde so we speak with some experience and knowledge as we voice our great concern for the severely/profoundly retarded and the impact the Chafee bill will have on their lives if it is passed as it is now written. We urge the Committee to seriously consider our objections to the bill and to make proper corrections to assure that quality institutional ca will not be phased out as it will always be necessary for our low func ioning retarded citizens. They are the most helpless, the most vulnerable to abuse and they deserve every consideration.

Respectfully submitted,

Virginia & W. B. Akers

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STATEMENT ON
MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT
SUBMITTED BY
VALAIDA S. WALKER, Ed.D., PRESIDENT
AMERICAN ASSOCIATION ON MENTAL RETARDATION

TO

SENATE FINANCE COMMITTEE
SUBCOMMITTEE ON HEALTH
APRIL 19, 1988

The American Association on Mental Retardation is the oldest and largest interdisciplinary organization of professionals in the field of mental retardation. The membership of 9,000 professionals is organized into divisions and subdivisions in the following areas: Administration; Communication Disorders; Education; General; Legal Process and Advocacy; Medicine; Nursing; Occupational and Physical Therapy; Community Services; Psychology; Religion; Social Work; Vocational Rehabilitation; Nutrition and Dietetics; Recreation; and Aging. The Association thus reflects the broad perspectives of diverse disciplines concerned with the problems of mental retardation. The Association prepares legislative goals each year in order to identify issues and positions important in the lives of persons with mental retardation, and engages in other activities such as amicus curiae briefs and public education in order to improve the understanding of public officials and the general public of the needs of persons with mental retardation.

As far back as 1975, in the publication "Rights of Mentally Retarded Persons", AAMR formally adopted the position that "Federal legislation is needed which is designed to promote the full participation of severely disabled individuals in community and family life." One of the purposes of the organization, as stipulated in the AAMR Constitution, is "to review and influence public policy in order to promote the welfare of persons with mental retardation." In response to an earlier version of this bill, our Legislative and Social Issues Committee prepared a statement of organizational principles related to the legislation which, in addition to the above statement, included the following:

"--The federal government has an important role in assuring high quality, adequately funded services and environments for all individuals with disabilities, regardless of age.

"--There should be a change in Title XIX funding mechanisms so that increased funding becomes available to community living facilities, so that more community living facilities are created, and so that inappropriate institutionalization of individuals with disabilities is ended.

"--Citizens with disabilities have a right to more precise and professional identification of their needs for habilitation services including vocational, educational, social, medical, leisure, and economic, as well as their residential needs.

"--There should be a shift in the federal funding of services for individuals with disabilities which reflects the actual needs of those individuals as identified in a precise and professional needs assessment.

"--Funding mechanisms should enhance potential for innovative services and delivery systems.

"--The principle of least restrictive alternatives should govern selection of living arrangement and habilitation services.

"--There should be mandated protective and advocacy services, both personal and systemic, provided to all disabled individuals, with appropriate hearing mechanisms for the parties to disputes. Proper consent and individual choice must be assured.

"--State compliance with legal requirements for planning, implementation, quality control and respect for clients' and other parties' rights should be federally monitored.

"--There should be individual case management and coordination for each person with a disability receiving specialized services. The case management and coordination should be provided by a professional with an appropriatly sized case load and an interest in and knowledge of each disabled person served.

"--Education to promote public awareness of the rights of persons with disabilities is necessary.

"--In order to enhance normalization opportunities, generic services should be used when they can adequately address the needs of individuals with disabilities.

"--When an individual receives benefits under Social Security Disability Insurance and, as a result, is found ineligible for SSI benefits, the person should be eligible for benefits under this Medicaid Reform Act.

"--When specific institutions are being phased down, improvements in the physical plant should not be overemphasized. Efforts instead should concentrate on high quality individualized habilitation plans, services, and staff-client ratios.

"--When specific institutions are being phased down, retraining of employees should be made available. There should be adherence to fair employment practices and standards for employees of private as well as public institutions.

"--Professional training needs of all service providers should be addressed.

"--Disruption in the lives of disabled individuals during the shift in federal financial emphasis should be minimized. Respect must be accorded to individuals' privacy, dignity, personal worth, and significant personal relationships."

One of our members, Dr. David Braddock, has been conducting extensive research entitled "National Study of Public Spending for Mental Retardation and Developmental Disabilities." He has found that: "Federal ICF/MR funding of $2.9 billion in FY 1986 represented three-fourths of all federal MR/DD financial assistance for services and 75% of all ICF/MR funds were deployed to underwrite institutional care. There has been virtually no change in the past three years in the proportion of total ICF/MR reimbursements allocated for institutional care. The ICF/MR

Program thus continues its strong institutional bias even though many states have begun aggressive community services development campaigns."

In another instance he has stated: "There is little doubt that the deployment of substantial federal funding to state institutions has simultaneously freed many innovative states to rebudget extensive funding for community services. However, given the potentially much larger constituencies for MR/DD services existing outside state-operated institutions, and the continuing and inexorable decline of the institutional census, the contemporary budgeting of ICF/MR funds predominantly inside institutions is anacronistic."

Another area in which we share the deep concern of Senator Chafee and his colleagues is that of quality assurance as it relates to the MR/DD program. Valerie Bradley, another AAMR member, and a recognized authority in the area, has stated that: "...quality is the promise that is made to the client and quality assurance is necessary to ensure that the promise is kept. To ensure that the promise of community integration -- a full life in the mainstream of the world of work and leisure -- is kept, quality assurance systems must be available that both monitor the fulfillment of the integration goal and that assist in facilitating the implementation of the concept. Notions like community integration are not self-fulfilling -- they need to be nurtured

and supported. The field of mental retardation and developmental disabilities is fairly good at housing and training people with mental retardation but the skills needed to encourage integration are not necessarily taught in professional schools.

"... Turning conceptions of quality into standards is a complex process in the human services field. ... In the human services field -- and particularly the developmental disabilities field -- multiple entities and perspectives contribute to notions of quality and to the setting of standards. The application of these standards is also complicated by the diversity of the provider community and the approaches applied to service intervention. The recognition that notions of quality are multi-faceted leads us to the conclusion that quality assurance systems must also employ multiple perspectives in assessing and applying quality standards."

"... now, more than ever, responsive quality assurance mechanisms are necessary to:

"* Protect the rights of vulnerable persons with more severe disabliities who are now and who will be living and working in community settings;

"* Maintain and live up to the trust that parents of individuals with mental retardation have put in the concepts of community integration for their family member;

"* Provide feedback to providers of service in order to assist them to improve and enhance their programs;

"* Respond to pressure from funders such as state legislators to justify and defend the efficacy of community programs;

"* Embody, in quality standards, the most recent developments in service technology and service provision, and, as a result, to provide programmatic leadership and vision; and

"* Ensure the maintainence of programmatic excellence over time."

The federal government has an important role in assuring high quality, adequately funded services and environments for all individuals with mental retardation, regardless of age. The manner in which the federal government exercises that role will largely determine where persons with mental retardation live, what the quality of their environments will be, what services they will receive, and whether they will have opportunities to develop their potential.

To date, federal funding policy has promoted and supported unnecessary institutionalization of persons with disabilities. Under Medicaid, large amounts of money have been available to remove persons with mental retardation from their homes and communities and place them in large isolated facilities. But only very small amounts have been available for support to families so that they can assist such persons in their own homes, or for other services which could prevent or postpone out-of-home placement. While some flexibility has been available under the waiver program, it has been inadequate -- the waiver program is a "waiver" from the program's primary direction and operating presumptions in favor of institutionalization. It is critically flawed in that it is time-limited, subject to the reluctance of some state bureaucrats to challenge outmoded but entrenched institutions, granted solely at the discretion of the Secretary, and insufficiently stable to create the trust needed by families and persons with disabilities as they make plans for their future.(Luckasson)

The time has come to reform the Medicaid program in a significant way. Congress should fundamentally restructure the Medicaid legislation as it affects people with mental retardation and other developmental disabilities and their families by reversing the very premises of the legislation. Instead of looking to institutional care as the principal system for providing services. Congress should look to home and community as the principal system. Instead of looking at the medical model as suitable for all people who have mental retardation or other developmental disabilities, it should adopt the developmental model. Instead of creating permanency of care in institutions, it should create permanency of care in the home and community by directing Medicaid funds toward home and community. Instead of having federal policy rest on out-dated knowledge about the supposed lack of ability of people who have disabilities it should have the policy rest on the current knowledge that all people who have disabilities, no matter the degree of severity, can be suitably accommodated in community-based education, habilitation, and medical service-delivery systems, and that they achieve greater development there than in institutional programs. It should fashion policy that recognizes that people with disabilities make good community citizens.

The American Association on Mental Retardation is strongly committed to a more appropriate system of federal funding for services to persons with mental retardation and other developmental disabilities. Our 1988 Legislative and Social Goals contains the statement the "The AAMR supports the Chafee - Florio Home and Community Quality Services Act". We stand ready to be of assistance to the Congress in any way we can as Congress seeks to address this most urgent problem in the lives of our citizens with mental retardation amd other developmental disabilities.

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AMERICAN HEALTH CARE ASSOCIATION

Testimony on
S.1673
The Medicaid Home and Community Quality Services Act of 1987

The Medicaid Home and Community Quality Services Act of 1987

Introduction

The American Health Care Association (AHCA) is the nation's largest federation of licensed long term care facilities. In addition to traditional nursing and residential care facilities the membership includes private intermediate care facilities for the mentally retarded (ICFs/MR) of over 15 beds.

AHCA welcomes this opportunity to offer comments on the Medicaid Home and Community Quality Services Act of 1987, S.1673 and its companion bill H.R. 3454. AHCA supports the development of a continuum of noninstitutional and institutional care of the developmentally disabled, however, AHCA is opposed to this legislation for several reasons. First, the proposal is not well understood. It is publicized as a bill to promote community services, not as one which will close existing facilities over 15 beds. These facilities include not only large state institutions which often cost over $100 per day per resident to operate but also the smaller privately run profit and non-profit facilities for the developmentally disabled which are reimbursed at much lower levels. Second, the proposal is not a concensus proposal; in fact, it is very controversial and initiated the formation of a nationwide coalition of parents and providers opposed to it. In a short time that coalition has gained thousands of members. Finally, AHCA is concerned about the "worst case situation" that could result from this legislation. If a state opts to include only mandated community services and if the institutions or community based facilities are forced to close, the service delivery system would be totally inadequate.

The legislation promotes the development of home and community based care by diverting payments from facilities over 15 beds. This method will eventually force most facilities to close. Without residential facilities there will be no continuum of care, despite the need for it. The proposal is based on the assumption that facilities over 15 beds, regardless of ability to deliver quality care, are bad. This assumption is not based on universally accepted principles that size and quality are related.

It is well known S.1673 will increase the costs of care: new services, new eligible populations and new bureaucracies are authorized and will have to be paid for. It is also known that community services cannot adequately fill the need of every developmentally person. While there is a need to expand community services, there is no justificiation to expand them at the expense of facilities based care. To create a program of increased costs yet narrow the scope of services provided for the varied needs of a diverse population will simply deny access to those who need 24 community care The current system lacks adequate community services; this proposal will replace it with one that lacks adequate facility based care. What the developmentally disabled need is a system that incorporates the full continuum of institutional and noninstitutional care, matches services to needs and includes a freedom to choose services.

Section by Section Analysis

The section on definitions authorizes new services in a Medicaid program. If services such as habilitation, case management vocational services and case coordination services, as defined in this section are added to current Medicaid plans, costs will increase.

In addition to expanding services, the definitions include an expansion of the population served. The definition of individual with a severe disability would expand to include individuals over the age of 22 up to age 50. The added populations will increase the aggregate cost of care. The definition also raises questions about those over age 50 who are excluded from participation. Recent nursing home reform legislation prohibits nursing home admission by many of these individuals. Between the two, those over age 50 may fall through gaps in the system.

The definition of a community living facility is based on the false assumption that size is related to the ability to provide care. If only small facilities are eligible for funding under the program, large ones will close and the continuum of care will not include a full range of services and settings.

Many of the community and family services authorized by this legislation are not medical services. For example, specialized vocational services, domestic assistance, and chore services are of a non medical nature. Authorizing these services as "medical assistance" clearly expands the Medicaid coverage to pay for them. The cost as well as the appropriateness of including these services under Medicaid should be seriously scrutinized. Can these services be offered to the developmentally disabled and not other Medicaid eligible groups?

Room and board services are excluded from coverage. This will result in an increase in federal SSI benefit costs of as much as $354 per person per month and should be considered when determining the total cost of the bill.

Among the requirements to implement the program are requirements for the state to promulgate standards to annually monitor all providers. The increased population of eligible individuals and providers will require a corresponding increase in the number of surveyors to monitor the program. In Texas alone an estimated additional 75 to 100 surveyors would be required. The cost of these larger survey teams will increase the Medicaid costs.

The requirement to transfer severely disabled residents of SNFs and ICFs within 40 months of identification of the service needs' is inconsistent with recently enacted nursing home legislation. That law requires mentally retarded and mentally ill residents of nursing homes to be assessed for service needs and allows certain long term individuals to choose to remain in the nursing homes rather than be forced to transfer to another setting.

A preadmission screening program to prevent inappropriate placement of individuals in SNFs and ICFs is to be established within 18 months of the effective date of S.1673. Because the recent nursing home reform legislation already requires such a system, this is a duplication which should be avoided.

Implementation of quality assurance system required will further expand the need for personnel. Quality assurance is essential to a good program; however, it must be recognized as an added cost, because it will require increased personnel.

It appears that several separate functions: survey, quality assurance, licensure and certification and third party evaluation will be required to assure appropriateness of services. Clearly there must be a way to develop a more streamlined process for assuring appropriateness. Resources could be better used to provide quality services in the first place rather than to judge them afterwards.

Prompt correction of deficiencies are required under Sec. 3(d). The word "prompt" implies that all deficiencies can rectified overnight. This is simply not true, especially when the deficiency may be the result of a shortage of available trained staff or physical plant conditions. "Reasonable" correction of deficiencies is far more realistic.

Sec. 3(d)(4)(B) is unclear. Does it mean that the state plan must include provisions for those individuals residing in institutions which are no longer receiving Medicaid or are closing? Are the provisions to be made outside the facility or can they be made inside the facility until an appropriate setting is found?

Under the proposal, the state is required to set forth procedures for advising individuals of available alternate services. Are only options within the family and community services program required to be presented? Is there any freedom to choose to remain in an existing residential facility and access community services? As noted before, this freedom of choice has been guaranteed for long term residents of nursing homes.

Current employees of private large ICFs/MR are threatened and discriminated against by this legislation. Only employees of public institutions are guaranteed job protection. The guarantee do not extend to employees of private institutions, even though this federal program will eliminate their jobs.

The maintenance of effort requires states to maintain funding community and family support services program at previous levels and to increase the funding according to the inflation factor. At the same time, maintenance of community residential or institutional support is frozen. The inflation factor is only activated in cases where the CPI rises 6% or more. With ICF/MR costs increasing at a rate of 10 per cent per year, it will not take long for the freeze to strangle facilities over 15 beds. Clearly these funding requirements establish a bias in favor of the noninstitutional services and will lead to the demise of the community residential facilities or institutions and to the continuum of care. It is also worth noting that the freeze would establish an unprecedented cap on Medicaid funded services.

Recommendations

AHCA believes the full continuum of care must be promoted. Developmentally disabled persons have a variety of needs and need a variety of services. Some, usually the most severely or profoundly disabled and multiple handicapped, need 24 institutional care where professional staff to respond to medical emergencies is nearby. Even in those states where home and community services are relatively well developed, there are individuals who cannot be appropriately cared for through group homes and noninstitutional services. Freezing payments to institutions and redirecting funding only to noninstitutional care would phase out institutions and a comprehensive level of care appropriate for the most severely disabled.

AHCA acknowledges that lack of community services is a barrier to appropriately transferring some residents of institutions to the community. However, closing institutions without a guarantee that the community services are available, adequate or appropriate can be likened to burning bridges behind us.

There are several vehicles currently available to promote the development of community services. First, the current Medicaid program allows states to be creative and flexible in developing a plan for service delivery to eligible populations. Several states already provide extensive Medicaid reimbursed community care for the developmentally disabled. These states demonstrate that a strong community program can be supported through the existing system. Further, the Medicaid Home and Community Services Waiver, the Section 2176 program is available to each state and is specifically designed to fund alternatives to institutional care. Some states have successfully used this vehicle to deinstitutionalized the developmentally disabled.

Finally, AHCA would support a proposal which either would not freeze funding for institutions or would grandfather the existing institutions and community facilities of more than 15 beds, without a freeze; yet, direct resources to enhancing community services at the same time. If such a program were to be implemented, there would be something for everybody and certainly more alternatives.

Conclusion

AHCA cannot endorse the system proposed under S.1673 system. It is based on an arbitrary size and premised on unproven theories. If enacted, many ex-residents of facilities will be isolated in small homes, uncared for and perhaps eventually forgotten or ignored.

Any changes in Medicaid must encourage a balanced approach to the care of the severly disabled. While the severly disabled have one thing in common -- disability -- they are a heterogeneous group and cannot be pushed into a narrowly designed system which works under certain circumstances.

There is a need for home and community care services for those who can make the transition from larger to smaller home like facilities. Unfortunately, many people are unable to develop skills necessary to live independently. These people may be profoundly retarded, blind, crippled, and suffering from a number of medical conditions. In addition to training, these people need nursing and therapy and custodial care from 24 hours a day. Is it practical or even possible to provide these services in small scattered settings? Even if the personnel were available, the cost would be prohibitive. The total cost of a nursing visit, a home health aide visit and a therapist visit could be as high as $100 per day. Add to this the cost of room, board, and custodial care and the total cost is much more than what Medicaid now provides, particularly to the private facility.

AHCA is concerned this legislation will appeal to those who are not well informed. We support the goal of independence; however, we know the proposed system will be disastrous for some developmentally disabled. They need and deserve a system which is based on the quality of services, not an arbitrary number of beds.

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April 5, 1988

The Honorable George Mitchell
Chairman
Health Subcommittee
Senate Finance Committee
176 Russell Senate Office Building
Washington, D.C. 20510

Dear Senator Mitchell:

On behalf of the American Psychiatric Association, a medical specialty society representing more than 34,000 psychiatrists nationwide, I am pleased to submit for the record our views on certain aspects of the Medicaid Home and Community Services Act (S. 1673). Over the course of the past sessions of Congress that Senator Chafee has introduced bills related to the delivery of community services, APA has commented on these and raised our concerns about those individuals who have dual diagnoses and who may not always be appropriate for a community setting.

As you well know, the tragedy of deinstitutionalization for the mentally ill has resulted in a homeless population with approximately 50-60 percent of these individuals chronically mentally ill. We do not wish to see this happen with the mentally retarded who may also have a mental disorder. The most prominent dual diagnoses noted among the mentally retarded include: severe behavior problems necessitating a large degree of environmental control and response; overt mental illness, such as psychiatric symptomatology, including schizophrenia and manic depressive disorder; self-injurious behavior resulting from biting, hitting and destruction of property; and other medical conditions. For multipally handicapped individuals, programs of habilitation may require a complex array of costly services. These services must also be avialable in the community if more emphasis is to be placed on community care.

Certainly, Senator Chafee's bill with its focus on community services in lieu of institutional care has been modified since its initial introduction three Congresses ago, but as you know the APA has been and continues to be concerned that appropriate oppurtunities for institutional care remain. The current bill will allow more potential in this direction as insititutions will not be overtly eliminated.

Please know that in response to Senate staff requests we are in the process of obtaining statistics on the numbers of dual diagnosis individuals in ICFMRs, but the statistical database is not complete and the data not new. More data may need to be collected so that the extent of the population with dual diagnoses is more clearly delineated.

As you contemplate making changes to the delivery of care to the population with mental retardation/developmental disabilities, APA hopes that you will carefully consider the needs of that uniquely vulnerable portion of the population with secondary or complicating diagnoses of mental or behavioral disorders. From time to time this population may at best be served by a larger insitutional setting with capacity for medically necessary multiple interventions.

Sincerely,

Melvin Sabshin

Melvin Sabshin, M.D.
Medical Director

MSS/ESS/wyg

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WRITTEN STATEMENT OF
THE STATE MEDICAID DIRECTORS' ASSOCIATION
OF THE
AMERICAN PUBLIC WELFARE ASSOCIATION

FOR THE
SUBCOMMITTEE ON HEALTH
COMMITTEE ON FINANCE
U.S. SENATE

HEARINGS ON THE MEDICAID HOME AND COMMUNITY
QUALITY SERVICES ACT OF 1987

MARCH 22, 1988

Mr. Chairman, members of the subcommittee, the State Medicaid Directors' Association (SMDA) of the American Public Welfare Association welcomes the opportunity to provide comments on S.1673, "The Medicaid Home and Community Quality Services Act." This bill, introduced September 10, 1987, by Sen. John Chafee (R-R.I.) would significantly restructure the way in which the Medicaid program provides services to mentally retarded and developmentally disabled individuals.

The major focus of the bill is to increase the opportunities mentally retarded and developmentally disabled (MR/DD) individuals have to receive services in home- and community-based settings. This would be accomplished through a policy of deinstitutionalization. Deinstitutionalization is supported by the states and is a policy states have actively pursued for well over a decade.

The home- and community-based waiver program, established by the Omnibus Budget Reconciliation Act of 1981, authorized the Secretary of Health and Human Services to grant states waivers to provide a broad range of home and community services to targeted populations. States have been strong proponents of providing services through non-institutional settings as is demonstrated by the number of states that have applied for and operated home- and community-based waiver programs. In 1987, 44 states had a total of 93 waiver programs, including model waivers, in effect. One third of these waiver programs are targeted specifically to mentally retarded and developmentally disabled populations. Although in many instances these waiver programs have not yet expanded to cover a large part of the eligible targeted population, state efforts in deinstitutionalization are clearly evident.

The process of obtaining approval for a waiver program is cumbersome, time consuming, and costly as SMDA has testified previously before this committee. States make a firm commitment of time and resources when applying for a waiver program with no assurances that, eventually, their efforts will result in an approved, operating program. The requirements HHS has developed in the final waiver program rules are very likely to deter, rather than encourage, waiver requests. Nonetheless, states continue to apply for new waiver programs, and to re-apply for continuation of existing programs. Furthermore, in testimony before this and other congressional committees, states have asked to be able to allow home- and community-based care services as an option under state Medicaid plans, thereby eliminating the need for a waiver.

SMDA Concerns:

(1) Limiting FFP for Institutional Care

While the states have made significant efforts to provide home- and community-based care, and support the basic policy of deinstitutionalization, the State Medicaid Directors' Association does not agree with a number of key provisions in S.1673.

Of greatest concern is the provision that would severely limit the amount of federal financial participation (FFP) available to states providing services to MR/DD individuals residing in larger institutions. The bill proposes to freeze the level of FFP available for services provided in large facilities to the amount the state received on behalf of non-elderly persons in such facilities for the fiscal year period prior to enactment. It appears that a misunderstanding exists regarding state efforts to move the MR/DD population out of institutions. S.1673 seems to presume that states continue to be financially biased in favor of institutionalizing Medicaid recipients, and that this bias will disappear if federal funding to institutions is capped. We disagree with the presumption that states are biased towards institutional care, and we raise serious objections to the bill's provisions to cap federal funding to institutions with 16 or more beds.

This committee is well aware of the numerous efforts in recent years to cap federal funding of the Medicaid program. The administration's annual budget proposals have sought to limit federal financial support for the Medicaid program by placing a hard dollar limit on federal financing available to state programs, which would change the nature of the program from an entitlement to a block grant. The states have vigorously and consistently opposed such a move as have members of this committee. Your leadership has deflected these proposals which would have placed an inequitable burden on states in providing services to the most needy of the nation's population.

Consistent with our earlier positions, we object to this provision in S.1673 that would cap federal payments for MR/DD populations residing in institutions containing 16 or more beds. This provision would force states to provide all Medicaid services to MR/DD individuals in a community-based setting even though this may not always be best for the recipient. Some mentally retarded and developmentally disabled individuals need the type of intensive, round-the-clock care that can be provided efficiently only in an appropriate institution. We do not believe the federal government should prescribe uniform sizes and locations for the provision of care. These determinations are best left to the state officials with experience, and incentive, under Medicaid to provide the types of care needed by this population.

If a state decides, appropriately, to continue to provide services to some individuals in existing institutions, that state would pay a financial penalty under this bill. Many of the costs associated with operating a larger facility are fixed and not affected by census levels. Thus the per diem cost would dramatically rise, but the state would not be entitled to receive appropriate reimbursement. The state would have to pick up a much larger share of the cost of appropriately providing services in a larger facility. Through this penalty, states may be faced with increasing pressures to make adjustments to other parts of their state programs to counteract the effects of their increased costs. This would not be a desirable situation.

(2) Using Medicaid to Provide Social Services

Another provision of the bill, section 1902(a)(49), mandates that states provide these four social services: (1) case management; (2) individual and family support; (3) specialized vocational; and (4) protective intervention services. This raises several issues for states. Some states do offer these services to targeted populations through waiver programs and other options such as services to pregnant women and children and prepaid health care. The mandatory nature of the provision in the legislation, however, represents a major step in the gradual shift for the Medicaid program from traditional medical services to greater emphasis on social services. The major shift in program focus for the MR/DD population under the provisions of this bill may open the door to widescale provision of social services and vocational/rehabilitative services than currently exist in the program. We do not disagree with the shift to a braoder array of non-medical services provided under the Medicaid program but are somewhat concerned over the approach through which these expansions have taken place. Expansions such as those contained in S. 1673 are often in response to the inadequacy or retrenchment of other federal or state/federal programs. We believe that other federal programs such as Title XX Social Services Block Grant and federally-funded vocational/rehabilitation programs are more appropriate programs through which many of these services should continue to be provided to the MR/DD population. If the Medicaid program is to be the primary or sole provider of many of these social services, it should happen as a result of a national mandate and commitment of adequate resources.

(3) Program Inequities

In addition, we are concerned that bills such as S.1673 may create inequities in the availability of services among the various groups within the Medicaid population. For example, the frail elderly are not a population covered under S.1673. Even though they would benefit from the kind of services proposed in S.1673, these services would not be available to most of them under the current Medicaid program, except through home- and community-based service waivers. As previously mentioned, the waivers are difficult to obtain and are not designed to meet the needs of a larger eligible population.

Medicaid directors recognize that in past years Congress has passed special legislation to target Medicaid services to a specific portion of the population -- most notably to infants and pregnant women. We understand that in passing such legislation, Congress is responding appropriately to significant pressure to deal with the alarming rise in infant mortality, and that the Medicaid program is one of the few available programs through which these problems can be addressed. However, the current movement to target a special mix of services to subgroups of the Medicaid population may lead to further program inequities.

(4) Cost Implications

Finally, we are concerned with the cost implications of S.1673. The bill would increase the level of services available to the targeted populations as well as significantly increase the number of individuals eligible for Medicaid over a period of years. The cost of community-based care is not necessarily, as some may assume, less expensive on average than institutionalized care.

If intensive care is provided to individuals in several small settings, rather than in one large institution, there could be significant inefficiencies. Professionals qualified to provide care and rehabilitation to disabled individuals are in relative short supply. Recruiting and training the large number of new professionals that will be needed will be a costly endeavor. It is doubtful that having more professionals available in large numbers of community facilities will be cost-effective, especially given other legitimate demands and the limits on resources we are willing as a country, to devote to health and social services. Thus, community facilities, as defined in S.1673, will not always be able to provide adequate staff and equipment for those most in need, unless such facilities become prohibitively expensive. While we are not proponents of the notion that cost considerations alone should determine the most appropriate settings for the delivery of services, we merely wish to point out that, in an era of diminishing resources and funding, some balances must be struck between the sometimes competing issues of cost-effectiveness and the most desirable setting for the provision of services.

The increased costs for this targeted population reflected in S.1673 will place further pressure on already strained state Medicaid program budgets. Such a significant expansion of cost for a relatively small Medicaid population may have the unintended consequence of adversely affecting the eligibility and service coverage available to other portions of the Medicaid population.

Conclusion

Although we have raised several concerns with specific provisions of S.1673, we emphasize again that Medicaid directors strongly support the basic thrust of the bill: increased availability of home- and community-based services as appropriate. The states have used the waiver program prudently and responsibly. There is no reason to believe that this commitment would change if home- and community-based services waivers become a less cumbersome state option. This option would avoid the delays and uncertainties that accompany the current waiver process and would, therefore, foster even greater state efforts to deinstitutionalize MR/DD individuals, as intended by the bill's sponsors. We urge the committee, in assessing this bill, to consider alternatives such as making home and community care available as a state option. Medicaid directors would be happy to discuss the key points raised in this testimony with committee members. We will continue to work with committee staff to advance the availability of home- and community-based care to the mentally retarded and developmentally disabled. Thank you.

WRITTEN TESTIMONY OF ROBERT ANGELES
MARCH 22, 1988

SENATE FINANCE SUBCOMMITTEE ON HEALTH
HEARING ON THE MEDICAID HOME AND COMMUNITY QUALITY SERVICES
ACT OF 1987, AND RELATED ISSUES

I would like to thank the Committee for allowing the opportunity for written testimony to be submitted, for the record, on this issue by concerned individuals.

My name is Robert Angeles and I'm from Springfield, Illinois. I have cerebral palsy and had a younger brother, David, who was multiply handicapped and profoundly mentally retarded - having spent most of his life in a state operated institutional setting. I do volunteer work for United Cerebral Palsy of Illinois and have done a considerable amount of research on issues related to individuals with disabilities on UCPI's behalf.

Based on personal impressions and research I have completed, I would like to state my position and that of United Cerebral Palsy of Illinois on the establishment and utilization of a national family support/community services program.

Many states are currently considering or employing some type of family support/community services program(s) to assist their developmentally disabled populations to participate in their own communities and establish their own independent lifestyles. Unfortunately, many of these State programs are not able to encompass the State's entire disabled populations. The reason for this lack of coverage is due to insufficient funding being available at the State level and/or the lack of a clear Federal statement which would allow the use of Federal monies for these types of programs. A Federal policy must be developed to answer these needs and problems facing the States and the populations served. The policy must be a directed, unified code - as would be the case with the passage of SB 1673, the Medicaid Home and Community Quality Services Act of 1987.

The concept of family support and community services is nothing new. Its origins can be traced back to the year 1601 with the passage of the Elizabethan Poor Laws, which provided local community supports for families that could not afford to take care of their poor and/or medically disabled relatives. This concept carried over to our American traditions. State and locally run programs would provide the disabled populations with needed care and services if the individual's family was not able. By the 1840's this original concept was tempered with the utilization and establishment of State institutions which were designed specifically for the care and treatment of the developmentally disabled/mentally retarded/mentally ill populations. These facilities were thought to be the best means of habilitation of the DD/MR/MI person.

The Great Depression of the 1930's caused a heavy financial burden on the States and their programs and institutions serving the disabled populations. Federal monies were being utilized from this point onto serve the States' disabled individuals. However, much of this funding would be spent on institutional settings.

By the 1950's, it was proven by several parent-sponsored groups that DD/MR/MI persons could be better served outside the institutional setting - in their own local communities through programs and services offered direct to the individual in his/her own home. Slowly, this local community concept gained momentum and, from the 1970's on, Federal legislation was enacted and/or amended to allot funds to be used for community-based programs.

Parents were/are asking for the necessary assistance and programs to help them keep their DD/MR/MI relative within the family setting and/or that these individuals be provided with the education, training, services and supports so they may live independently in their local communities.

Currently, our national policy is a haphazard collection of statutes, rules and regulations, administrative and judicial opinions - which provide some answers and funding to the States but are not a single unified directed code as would be the case with the passage of the Medicaid Home and Community Quality Services Act of 1987.

There are four basic reasons why there is a need for family support and community based services...

1. Families have a basic right to be together as a whole - separation of the DD/MR/MI relative is an undue hardship and cruel punishment - just to provide services which could easily be provided in the family home - if assistance is available for the family to utilize.
2. DD/MR/MI individuals have constitutional rights, just like any other citizen, to live in their own communities and have the opportunity to attain their highest degree of potential for independent living.
3. Many individuals in facilities for the disabled are not being appropriately served since the specific and unique needs of the resident cannot be handled in the facility setting without great costs, in terms of monies, and staff time. These costs would be less in a family/community setting. If local communities are utilized to help the family/individual attain the needed assistance and services, institutional settings could be gradually phased out and the staff from these institutions employed in the community to assist the family/individual partake in the local society.
4. A general legislative focusing is necessary to avoid confusion, denial, or inappropriate services/placements of the disabled person in community or institutionalized settings.

Family support/community services are appealing today for the following reasons...

1. Better evaluation and assessment methods give service providers a greater understanding of the problems, needs and potential of developmentally disabled/mentally retarded/mentally ill individuals in living within their local communities.
2. An advanced medical and technological approach assists these individuals to participate in the local community.
3. Studies have proven the cost effectiveness of family support/community services - such as the Pennhurst Longitudinal Study.
4. A willingness by the Federal Government to fund Home and Community Based Programs, as seen by the passage of the Omnibus Budget Reconciliation Act of 1981, and subsequent reconciliation acts. For example, in FY 1985, Illinois received a total medicaid expenditure of $875,284,000. Of that amount $215,970,087 went to Intermediate Care Facilities for the Mentally Retarded and $12,596,000 went for home and Community Based Waiver Programs. Though not a significant amount, it does indicate that the Federal trend is shifting towards community based living and services for DD/MR/MI citizens.

Many States are starting to carefully develop and implement programs which utilize the family as the cornerstone for providing services and assistance for developmentally disabled/mentally retarded/mentally ill individuals. These programs emphasize the goal of assisting the disabled individual in obtaining his/her highest level of habilitation and potential in the mainstream of society. However, funding and a uniform statement of goals, duties and rights at the national level is necessary to ensure the nation's disabled are provided an equal opportunity to participate in society.

I do strongly advocate that the Committee consider the goals and hopes which can be attained if the Medicaid Home and Community Quality Services Act of 1987 is enacted into law.

I commend you on your efforts in seeking further comments and information regarding this issue. Again, I would like to thank the Committee for this opportunity to be heard. If I can be further of assistance, please contact me.

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Review and Recommendations
Senate Bill 1673
The Medicaid Home and Quality Services Act of 1987

Written testimony of The Friends of The Anne Grady Center
1525 Eber Road, Holland, Ohio 43528

We are providing this testimony on behalf of an organization comprised of parents/guardians and friends of the residents of The Anne Grady Center a residential facility for 96 profoundly/severely retarded adults.

We submit this written testimony as an expression of our opposition to Senate Bill 1673 and request the inclusion of the following in the record of the public hearings on Senate Bill 1673.

1. The proposed freeze on Medicaid funding applies only to the larger institutions and is coincident with the features of the proposed legislation that would create new survey procedures and standards. These new procedures and standards may cause an increase in expenditures by the institution in order to remain in compliance. Provisions in the legislation that restrict funding adjustments to that portion of the CPI percentage increase that exceeds 6% are wholly inadequate to maintain a viable facility. Provision should be made to assure funding to meet all current and future Federal Standards; along with regulations to assure increases at least "in step" with inflation. This bill does not impose any funding restriction on the facilities it authorizes.

2. The proposed legislation mandates the transfer of the residents of a facility with 16 or more beds, even though in compliance with Medicaid regulations, which is in direct conflict with Section 1902(a)(23). We cannot concur that this provision will provide "more appropriate residential settings". The profoundly and severely retarded will derive no benefit from the trauma of transfer from familiar people and surroundings. They will continue to need assistance in daily living and to be directed in all activities. They cannot benefit by the loss of on site medical assistance, habilitation programs and attentive 24 hour care in the sheltered environment they require.

2a. The automatic presumption that an institution is unsuitable for the provision of care cannot be supported by data. The provisions for the involuntary transfer of residents from these institutions does not provide any meaningful rights to the individual, their parents or guardian. Further, there is no provision for an appeal of a transfer plan from a large institution (ICF/MR) even though the facility is in full compliance with Medicaid rules. These mandates are in opposition to long standing rights and we ask that revisions be made to restore the right of parental/guardian approval of any transfer or habilitation plan.

3. We believe that the waiver provisions of this legislation unnecessarily abridge the rights of individuals to freedom of choice and equal access to services. There does not appear to be any justification for discrimination of this type. In addition, the individuals that wish to remain at home should be provided medical assistance under Section 1915(c)(1).

4. The lack of Federal Standards and Regulations to govern the operation of the facilities as provided for in S. 1673 may cause a degradation in the quality of care and an unequal application of Medicaid funds. We recommend that the regulations that implement Section 1905(d) be applied to all residential facilities regardless of size.

5. The desire by some to save money, or the hope by others to improve services by closing large institutions, has not been confirmed by experience. There is ample evidence to show that transfers to small facilities accomplishes neither; rather it is the quality of services provided by the institutions and the stable, protective environment that can most benefit the residents at least cost due to economies of scale. The unit completeness of a larger institution has the singular advantage of assuring humane treatment through the presence of professionals of all disciplines to provide medical services and to implement other programs.

6. Section 3 of this legislation includes an amendment to Title XIX to create a new Section 1921 which merely reiterates much of what already exists under various sections of Title XIX and available under section 1915(c). This bill may be misleading in that it mandates only the

following: Case management services, individual and family support services, specialized vocational services and protective intervention.

7. This legislation would create a new bureau whose responsibilities would be to administer the provision of services under Sections 1921 (as structured in the bill), 1905(d), and 1915(c). The thrust of this provision appears to be to control all aspects of the regulations regarding the provision of services to the mentally retarded. However, the Secretary is specifically restricted from establishing standards governing the provision of community and family support services. Thus, a dual set of standards for residential facilities would be established based on size rather than the services required by the residents to safeguard their health and well being. A resolution, of the inconsistency of dual standards, should provide that all facilities be licensed under Section 1905(d), regardless of size. Federal regulations are required to assure a uniform standard of quality and compliance.

8. The amendment to Section 1905(d), as proposed, would strike out "a public" to insure inclusion of all intermediate care facilities for the mentally retarded (public and private) in the affects of striking paragraph (3) which deletes the State maintenance of funding requirements for ICFs/MR. The inclusion of a new paragraph (3) followed by a new paragraph (4) provides for new admission criteria to an institution and mandates that private facilities cooperate, by written agreement, with the state in carrying out the state transfer plan. These amendments clearly revoke the right of freedom of choice. Current provisions of law require a comprehensive evaluation, a written individual habilitation plan and a review (by professionals) of the appropriatness of an admission to an ICF/MR. We submit that no useful purpose is served by these amendments to 1905(d) and should be deleted from the bill.

9. The provision that a State Plan submitted under Section 1921(c) of the subject bill, need only meet the requirements of Section 1921(d) to be in compliance with the provisions of the bill should be deleted. This provision would render the other requirements of the state plan meaningless.

10. The newly enacted Section 1919 titled "Correction and Reduction Plans for Intermediate Care Facilities for the Mentally Retarded" establishes procedures to be taken when a facility is deemed to be not in compliance with Medicaid regulations [1905(d)]. As one of the two options, a state may transfer the residents and provide them with home and community services. Thus Section 1919 becomes an extension of this legislation and provides the vehicle to close an institution and the only option to those being transferred is the acceptance of admission to a small facility. This is still another infringement on the right of freedom of choice as provided for in Section 1902(a)(23). In addition, the proposed amendment to Section 1919 would remove all restrictions and time limits to closing "large" facilities.

We do not believe that the solution to the problem of providing services for the mentally retarded lies in closing "large" facilities. Freezing funding or reallocating money within current costs only harms the most fragile segment of the mentally retarded. Quality of service and humane care cannot be equated to the size or location of a facility; nor should the denial of basic human rights and safeguards to care be a method of reducing costs.

The standards that must be met to qualify for Medicaid funding were established to abate the inhumane conditions in residential facilities for the mentally retarded. These conditions were unrelated to size; rather it was the lack of adequate funding, standards, and enforcement. Much has been accomplished in providing quality care for the profoundly or severely retarded. We believe a more positive proposal for the expansion of services can be developed without a regression in this care.

We believe an array of residential services can be made available that more adequately reflects the various needs of the individuals.

We ask that Senate Bill 1673 be held in committee in order that a more positive response to the needs of all the mentally retarded be developed.

Sincerely,

The Officers of The Friends of The Anne Grady Center

Jan Bratton
Jan Bratton, President

Alice Soule
Alice Soule, Vice President

Walter Grady
Walter Grady, Treasurer

Betty Michelson
Betty Michelson, Secretary

Chuck Winters, Special Projects

Statement of Associaton for Retarded Citizens of Maryland to Senate Finance Subcommittee on Health in Support of S. 1673

This statement is submitted on behalf of the Association for Retarded Citizens of Maryland by Ralph J. Moore, Jr., President, and Bernard A. Gould, Chair of the Federal Government Affairs Committee, of the Association. We represent several thousand mentally disabled person in the state and their families or other care givers.

Over the past several years, there has been a consistent nationwide program to move persons with developmental disabilities from large, 24-hour care institutions to smaller family-type facilities located in the community where the residents will have greater opportunities to participate in the normal activities of community life. Unfortunately, that trend has been slowed and in some cases, almost aborted, even though the greater majority of persons concerned with the interests of disabled individuals agree that small, family-oriented community residential facilities are the most desirable for those individuals.

In the case of the nation's homeless population, the essential element in the solution of that problem is a substantial increase in the number of available low-cost housing units. With respect to our developmentally disabled people, there has continued to be over the years long waiting lists of individuals seeking community residential facilities, or local day activity programs. In the state of Maryland, for example, an official census prepared for the Developmental Disabilities Administration listed 5,523 persons seeking such services as of July 1, 1987. That waiting list number unfortunately has remained high, year after year after year and it must be recognized that the figure represents only those who have made their needs known. All the experts who deal with the problem acknowledge that many other disabled people exist in the general population with serious and ever-growing needs who have not come forward because these care-givers are too proud to seek help, are ignorant of the fact that services, although limited, do exist or because they feel that in the face of long-existing waiting lists, an application for residential facilities would be a useless gesture. That the problem is a serious one is made plain from the fact that, among the adults with mental retardation on the waiting list, 37% indicated that their need for residential services was urgent. As with the homeless, the essential element in the answer to the problem of the seemingly intractable waiting lists, is an increase in the number of family-size community residential units and an increase in the number of local day program activities.

While the state readily concedes the need for additional community residence and additional support services, why does a sufficient increase not take place? The state contends that it is because of a lack of funds. In its official "Users Guide," the state's Developmental Disabilities Administration (DDA) informs applicants that "The length of time before you receive services from the DDA depends on the amount of money that the DDA has to spend on services . . . . While the DDA tries to serve as many people as it can, there are many more people asking for services than there is money to buy the services being requested." It is here where we believe that S. 1673 can bring about a major improvement.

The bill would mandate a major re-allocation of Medicaid funds flowing to the states for the care of those individuals with such severe disabilities as to qualify them for Supplemental Security Income benefits. At the present time, the SSI provisions have a built-in bias favoring the care of disabled people in the larger title XIX certified long-term care facilities, i.e., those with 16 or more beds. (Only under a restricted time limited waiver system do some such individuals presently receive some community based support services.) Thus the bulk of the SSI funds received by the state are used to maintain the large institution-type residential facilities which, as indicated above, are tending to have smaller and smaller populations. However, when an individual is moved from the larger ICF/MR facility to a less restrictive community residence, the large per capita costs of his or her care are not automatically switched by the state to fund community services. The community care system must still scramble for adequate financing. Under S.1673 the federal financial participation (FFP) in the cost of maintaining the large ICF/MR facilites would be limited to the amount the state received on behalf of the severely disabled under 65 years of age in the fiscal year previous to the date of enactment, plus any amount of inflation exceeding six percent. Thus, the declining population in the large institutions could continued to be accommodated there if they so desired and if it was found that a community residence and local support services would not more appropriately satisfy their needs. After enactment, the state instead would be required to amend its Medicaid program and to set up an implementing strategy by which it would provide an array of community and family support services including at least, case management, individual and family support services, specialized vocational services and protective and advocacy intervention services. A host of other optional support services could also be provided by the state under its Medicaid plan for severely disabled people to assist them in carrying on a more normal living situation in the family home, a foster family home or another community living facility.

The statutorily stated policy of the state of Maryland is "to foster the integration of individuals with Developmental Disabilities with the ordinary life of the communities where these individuals live and to support and provide resources to operate community services to sustain individuals with Developmental Disabilities in the community, rather than in institutions." However the state administration regularly has been unwilling, and contends that it is unable, to provide sufficient funds to fulfill that expressed policy and thus those persons with a clear-cut and urgent need for community support services remain on waiting lists year after year. By limiting the funds which will therafter be allowed to be placed into institutional care systems, the state will be encouraged to commit a greater share of its budget into community and family support services. We believe they will do so and thereby be in a position to fulfill the additional statutorily expressed policy (effective as of July 1, 1986 - Sec. 7-204 of the Md. Code, Health-General Article) of eliminating "over a five-year period the number of mentally retarded and non-retarded developmentally disabled individuals who are on the waiting list for appropriate community services and programs".

Some parents have expressed concern about the quality of the services to be provided in the community and the likelihood of those services being continued in the future. We are satisfied that the detailed and carefully crafted provisions of S.1673 dealing with the Medicaid plan and implementation strategies required to be placed in effect in each state will satisfy those concerns. For example, the state would be required under its Medicaid plan to expend from non-federal funds at least the amount it spent during the base year period for community and family support services adjusted for inflation (Sec. 3[e]) and outline its specific objectives and a projected schedule for expanding and improving community and family support services over a five-year period. (Sec. 3[d]). It must also establish procedures to ensure the continuity of funding and provision of services for the disabled person when the entity which had been providing those services voluntarily discontinues operations or is terminated from the program. Extensive provisions are contained in S. 1673 to assure that the services provided the disabled person meet the needs expressed in his or her individual rehabilitation plan and that those services meet and are maintained to a high quality standard. Adequate appeal procedures are required to be provided for a spouse, parent, guardian or other family member to use in case those quality standards are not met or the required services are not provided. We believe the legitimate concerns of the developmentally disabled person and his family or guardian have been carefully considered in the drafting of S. 1673 and that its provisions adequately assure that those concerns will be protected.

For almost five years parent and advocacy groups have struggled valiantly to bring about sufficient reform in the Medicaid system so that they could be assured of a real choice in having the needs of the developmentally disabled family member met in the setting they deem most appropriate and to give the States the flexibility to serve those person in their family homes or in community-based, family-scale integrated environments. S. 1673 will be of tremendous help in achieving those aims. In its present form it has nationwide support and its passage is long overdue. We call on the sub-committee to report it out favorably without further delay.

MARCH 23, 1988

THE FINANCE COMMITTEE,

AS THE OLDER PARENTS OF A TWENTY-TWO YEAR OLD PROFOUNDLY RETARDED DAUGHTER WE ARE AGAINST HB 3454/SB 1673- MEDICARE HOME AND COMMUNITY QUALITY SERVICE ACT OF 1987.

OUR DAUGHTER RESIDES AT FORT WORTH STATE SCHOOL. WE WISH SHE COULD HAVE STAYED HOME, BUT DECLINING HEALTH FOR BOTH OF US HAS PREVENTED THIS. OUR DAUGHTER MARCHEL, LIVED AT HOME FOR FOURTEEN YEARS AND DURING THAT TIME WE USED ALL THE PROGRAMS AND FACILITIES THAT ARE OFFERED TO A RETARDED PERSON. WITH THE KNOWLEDGE OF HOW LITTLE THE COMMUNITY HAS TO OFFER WE FEEL THAT THE STATE SCHOOL IS THE LEAST RESTRICTIVE AND WE WISH HER TO REMAIN AT FORT WORTH STATE SCHOOL.

AS AN EXAMPLE, COMMUNITY DOCTORS AND DENTISTS HAVE REFUSED TREATMENT TO MARCHEL. HAVING AN INFIRMARY AND DENTAL CLINIC ON THE CAMPUS OF THE STATE SCHOOL HAS HELPED TAKE CARE OF OUR DAUGHTERS MEDICAL AND DENTAL PROBLEMS.

THIS BILL WOULD TAKE AWAY FUNDING FROM THE LARGE FACILITIES. IN MANY CASES THE RETARDED WILL NOT BE SERVICED AS WELL REGARDLESS OF HOW MUCH MONEY YOU PUMP INTO THE COMMUNITY. IT HAS NOT BEEN PROVEN THAT THE COMMUNITY SERVICES ARE CHEAPER THAN THE STATE SCHOOLS WITHOUT LOSING SOME OF THE BENEFITS.

WE DO NEED BOTH COMMUNITY HOMES AS WELL AS STATE SCHOOLS. YOU SHOULD NOT DESTROY ONE FOR THE OTHER, AND PARENTS SHOULD HAVE THE **CHOICE**. THE PROFESSIONAL EMPLOYEE IS TOO WORRIED ABOUT THEIR JOB TO MAKE THE TOTAL DECISION AS TO WHAT IS BEST FOR THE RETARDED PERSON. THE PARENT IS THE ONLY ONE WITH THE TRUE INTEREST OF THE RETARDED PERSON.

PLEASE DO NOT REDUCE OR CLOSE THE STATE SCHOOLS, THEY **ARE** THE BACKBONE OF ALL SERVICES FOR THE RETARDED!!!!!!

YOURS TRULY,

Mr. & Mrs Paul W. Barnes

MR & MRS PAUL BARNES
4001 CORNELL DR.
GARLAND, TEX. 75042

April 16 1983
Mrs Vernon Bernhold
2343 Alpine Way
Dayton Oh. 45406.

Dear Mr Lewa Wilcox:

I hope that bill 1673 does not go through. My son cannot be in a residential home and he needs help like any other retarded. He is deaf and retarded.

Yours Truly,
Mrs Bernhold

TESTIMONY ON MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT

By Dr. John Heffelfinger, Medical Affairs Administrator
Bethesda Lutheran Home
Watertown, Wisconsin 53094

Prepared for the March 22, 1988, Hearing
Held by the Subcommittee on Health of the U.S. Senate Committee on Finance

You are to be congratulated for your interest in the needs of individuals with mental retardation. You have my thanks for that interest. I also want to thank you for the opportunity to express my concerns about the medical care given, and in some cases not given, to persons with mental retardation.

How do I know about their medical problems? As a pediatrician, I have had 35 years of experience in providing care to all types, ages, and levels of individuals with mental retardation. It has been a privilege to serve them medically and, with parents and other professionals, to help in the struggle to obtain access to proper care wherever they live, home or institution.

BACKGROUND

My name is John Heffelfinger. I am a pediatrician. My work has been in private practice, as well as helping in large institutions and teaching medical students and residents as a Clinical Associate Professor in the Department of Pediatrics at the University of Michigan Hospital and Medical School. At the present time, I am serving persons with mental retardation as the Medical Affairs Administrator at Bethesda Lutheran home, Watertown, WI.

In addition to our main campus in Watertown, we operate 26 community living facilities (group homes, intermediate care facilities and supervised apartments) in 11 states, serving nearly 700 children and adults.

When Bethesda was started, there were no schools for even educable retarded students. Soon the need for training for lower functioning individuals became obvious also. We now serve ONLY those at the severe and profound levels in Watertown. Many are handicapped by severe behavior/psychiatric disorders or are medically very fragile or elderly.

Because we provide a full spectrum of care and currently serve retarded individuals from 31 states and one foreign country, I have seen the positive and the negative aspects of institutions as well as group homes. I have also visited other group homes and institutions besides our own, including state and private facilities.

MEDICAL CONCERNS

My introduction to the problems of mentally retarded persons was in a small town 35 years ago. I chose this location for my private practice because the smaller communities have trouble getting services. This was epitomized especially by the mentally retarded youngsters - there were no schools and no therapies for them in those days.

Now they do have schools, but they still are having trouble getting the needed therapies and medical interest, knowledge and expertise. Some practitioners refuse to care for them or encourage parents to admit them to mental retardation facilities so they (the doctors) won't have to treat their complex problems. In some situations today, the group home clients are given very cursory exams. Very little interest may be shown in their individual problems, unless they are cardiac or pneumonia or diabetes cases. Emotional needs or rehabilitative deficits may be overlooked.

Lest you think that this happens only in small towns, you need to look a little closer. In all fairness, there are many fine physicians who are very concerned for these clients, but often they are lacking the background to pick up a possible familial disorder, or the need for further therapy or rehabilitation.

How many doctors know how to handle the anticonvulsants, or the interaction of second or third seizure medications, or what would happen with the addition of a still different medication? What if the familial disorder were never recognized? Or what if they did not recognize the specific disorder associated with mental retardation (over 300 causes of retardation have been discovered and many are still unknown) - and what if that disorder has a higher than usual malignancy rate as an additional complication?

Since my background is medical, I started with my own profession, but I assure you that similar situations exist within most professions. In many communities, hospital employees may be heard sighing, "Oh, not another one." And, what is dental care like your community? Some may have several dentists who provide excellent, concerned care, but other towns and cities may have none.

There really are few experts - medical or otherwise - and they, for all practical purposes, may not be accessible to many families.

Conclusion: Simply providing money for group homes (although that is important) does not guarantee quality care, or even adequate care.

SERVICE NEEDS AND ECONOMICS

Who needs the services of larger centers like Bethesda? At some time in life, possibly anyone with mental retardation! Not only do we serve all levels through a variety of settings, but our main campus has a diagnostic center, an outreach program that is hard to match, a training center for professionals (including pastors, parents and staff), plus a resource center and consultative services in most areas.

We have short term care and residential services for:

1) Retarded students tossed out of public or private schools (this does happen even today!),

2) Retarded individuals whose physical or emotional trauma has become too great a burden and the families can no longer cope,

3) Persons with extensive medical needs,

4) Those with problem behaviors and/or psychiatric disorders.

Among our admissions are many who have never had adequate training or medical care.

Yes, there are communities with EXCELLENT facilities and staff, but they are not in the majority in this field at this time. It is interesting that, although Madison, WI, has a good reputation for providing services, we still have referrals from there for services and second opinions and requests for admission.

On the other hand, there are many community homes that do not have adequately trained staff or appropriate management, plus they have no way to judge the quality of medical care given. These organizations may be very dedicated, but lack the skills and thus will not serve their clients appropriately.

Places like Bethesda can provide better trained staff, more therapy, more class time, extremely short travel time, and broader services - plus we can provide it cheaper. If you lump all the required services together (housing, staffing, medical care, educational and vocational training, therapies, etc., in the community), it will cost more in most cases in smaller settings than in a larger center.

To provide appropriate medical care for the hard-to-serve at a cost that is financially feasible necessitates a nucleus of experts (doctors, therapists and psychiatrists). This can only be accomplished in specialized units/clusters/complexes, and this bill makes no provisions for new facilities of this type.

Simply freezing the amount currently received by each state from the federal government is inadequate, illogical and discriminatory. Because the deinstitutionalization effort has been underway for some time in many states, most residents left in institutions are unlikely to be adequately and economically served in smaller, more isolated facilities. Most will remain in larger settings because of multiple service needs. However, assuming an inflation rate of close to 6% a year, S. 1673 will reduce the income of these larger facilities to half its present purchasing power in 16-1/2 years, making it impossible for them to continue operating. Thus it is obvious that, despite what its proponents say, the ultimate goal of S. 1673 is the elimination of all facilities of more than 8 beds.

Conclusion: Funding new facilities and services through estimated savings from a freeze on institutional funding is inadequate and unacceptable. It will eventually:

1) Cause the demise of even the good, large facilities.

2) Result in inadequate care for hard-to-serve mentally retarded individuals.

3) Have unforeseen **ramifications** due to the nursing shortage, which experts predict will last at least 10 years. Nurses currently are leaving their profession to go to higher paying, less stressful jobs. As the S. 1673 takes its toll, the nursing flight from the mental retardation field will escalate because there will be LESS funds for salaries than now.

Therefore, WE STRONGLY URGE:

1) Eliminate the freeze on funding for persons in institutions. Instead, let's enforce the laws now on the books and require these facilities to provide active treatment. Those that don't meet the standards should be closed and funding should be made available for the alternate placement of their residents.

2) Expand the funding provided in S. 1673 to include 16-bed homes (this enables two people to share a room and makes more sense than 15-bed homes) - and allow clusters of at least three such facilities, and preferably five, both for economic reasons and quality care.

3) If the freeze is retained in some form, specify that residents of public and private facilities are to be funded equitably. In the past in Wisconsin, private facilities came under different laws, and consequently under different funding, than public ones. Although this has been changed, it could happen again if the freeze results in a shortfall for state facilities.

FREEDOM OF CHOICE

What about choices? If mentally retarded individuals can be given better services at our main facility and for less cost, why can't the individual/parent/guardian choose that option? Parents often send their normal child/children to boarding schools or private schools. Undoubtedly, some of you or your colleagues have utilized such a facility. When you or your children went to college, weren't choices made? Aren't large facilities of higher learning receiving forms of governmental funding/benefits? Isn't this discrimination to deny the same choice to retarded people and their families? It is not equality...and it is proposed for the segment of our population that is least able to complain. When you choose a school, a doctor, a hospital, a service of any kind, you want the best and most reasonable for your family! What is the difference when it is a family that wants their retarded child to be served in a facility like Bethesda? Isn't this also a normalized approach?

Moreover, because funding is administered by states and ultimately by counties/zones, it is almost impossible for mentally retarded individuals to move out of state or to a different city/county where more adequate services exist or will become available.

Conclusion: S. 1673 must be amended to provide assurance of freedom of movement for individuals with mental retardation and freedom of choice for them and their families. Currently the bill provides for decision-making by an interdisciplinary team in which family and individual could be over-ruled. It mentions nothing about reciprocity between counties/states, etc.

WHAT DETERMINES QUALITY

Institutions - and group homes - may be good or bad. Size has nothing to do with quality. I have seen some group homes that were more institutionalized than our largest facility.

Quality of care is a tremendous variable. It is assured only through hard work and good administration. At Bethesda, we have both. We have also established our own internal quality assurance department.

Where are the best-trained medical and diagnostic people in this field? Usually at the universities, but they serve only a very few of the total number of persons with retardation. Where are the next best equipped and trained professionals? At the larger facilities like Bethesda! It has taken years to find and train professionals of the caliber that we have now. We are a minority, but a potent force to help individuals, families, schools, physicians, therapists, etc. Let's not destroy resources of this kind through legislation like S. 1673 in its present form.

Just a personal concern: If this legislation passes and eventually we are forced to place all our residents in the community, do you expect me to make house calls to 55 different locations? Because of the difficulty of finding good medical care at some of our group home locations, we have begun to experiment with interactive video as a means of training physicians to serve our residents, but it will be a long time until that becomes practical and results in adequate medical care in isolated locations!

What about the rest of the professionals? Will they be narrowed down to serving only a handful also - and will those persons who need their services have to travel long distances and spend hours in waiting rooms to get the care and consultation they require, because there will no longer be any major care centers for the hard-to-serve?

Conclusion: Let's eliminate our size-related bias and concentrate on quality. That means providing funding for a full spectrum of services, including workshops.

The greatest deterrent to placing more people in the community today is not funding for group homes but funding for workshops and training. Currently at Bethesda group homes in several states, we have to pay sizeable fees to enable our residents to attend workshops. Let's attack the need for services, rather than feuding over size of facilities.

FINANCIAL CONSIDERATIONS

At Bethesda, we are able to serve the hard-to-serve only because of the generosity of our supporters and volunteers. It is unlikely that our supporting congregations and individual donors will contribute to public programs. Therefore, if private facilities like Bethesda are eventually crushed by the S. 1673 freeze, the load for taxpayers will be even heavier than at present.

Nowadays, the federal standards for quality care require that all facilities provide "active treatment," even for the elderly residents who are mentally retarded. The problem, however, is that the funding even now does not cover all the staffing and services required to provide training programs which meet the regs. Federal and state Medicaid allocations for Bethesda residents currently cover only about 60% of our actual costs to provide the quality services which we agree are necessary. Consider then what will happen if a freeze takes effect.

AND FINALLY

Group homes and other community living options can offer many opportunities for happy and contented family living; they can be learning, growing, motivating places. But, they also can be a source of abuse, aggression, sexually transmitted diseases and ill health in general. My point is that the lowering of skill levels for residents of group homes, inadequate training programs, and unskilled supervision make the group home an easy place to get "lost." Finding good group home staff members is already one of our most difficult tasks, and our daily papers regularly carry ads for foster parents - where will adequate caretakers be found when thousands more group homes are funded by S. 1673? The answer is not nearly as simple as S. 1673 makes it appear. It will require higher salaries and more benefits than are the norm today.

While the goals are laudable, this process is not something to be rushed or forced. Rather, we must work at it steadily and carefully to assure that mentally retarded people do not become the street people of the future as happened when institutions for the mentally ill were depopulated.

I do not envy your task as Senators. You make decisions that may determine how many die in combat, or on the highways, or by drug overdoses, or what kind of medical care will be available to parts of our society...and not just to persons with mental retardation.

We don't want to add to your burden but whatever decision you make on this legislation will decide whether one or even the next two generations of this underserved population will have appropriate care and protection. Equality and quality are needed for these people who happen to be mentally retarded.

Options are available. We at Bethesda are one of them...and by the grace of God a good one. We want that to continue. More services are needed - but not at the expense of the good programs and places that are now doing a good job.

Thanks for the privilege of sharing our love for these individuals with you. May God bless you and your families as we serve our clients and constituency.

Dr. John Heffelfinger
Bethesda Lutheran Home
700 Hoffmann Drive
Watertown, Wisconsin 53094
(414) 261-3050

MARCH 19, 1988

THE FINANCE COMMITTEE,

AS THE PARENT OF A FIFTEEN YEAR OLD PROFOUNDLY RETARDED SON, I HAVE GREAT CONCERN ABOUT HB 3454/SB 1673, THE MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT OF 1987. MY SON LIVES AT FORT WORTH STATE SCHOOL AND THAT IS THE NEXT BEST PLACE FOR HIM. THIS BILL WOULD TREAT ALL DISABILITIES THE SAME, MENTAL AS WELL AS PHYSICAL, I WOULD GLADLY EXCHANGE MY SON'S MENTAL LIMITATION OF A TEN MONTH BABY AND MANY HEALTH PROBLEMS FOR ANY PHYSICAL LIMIT. THERE ARE SO MANY WAYS TO OVERCOME OR HELP A PHYSICAL LIMITATION BUT A MENTAL LIMITATION CAN ONLY GO SO FAR. WHEN I WAS TOLD MY SON HAD BRAIN DAMAGE AND THEY WERE NOT SURE WHETHER IT WOULD AFFECT HIM MENTALLY OR PHYSICALLY I PRAYED FOR IT TO BE PHYSICAL, BUT HE AND I WERE NOT SO LUCKY. MEDICAID IS ALREADY STRAINED, BY ADDING TO THE LIST OF ELIGIBLES IT WILL INCREASE THE COST BY MILLIONS EVEN IF IT ONLY PAYS A SMALL AMOUNT PER PERSON.

THIS BILL WOULD UNDERMINE THE ALREADY STRAINED STATE SCHOOL SYSTEM. THE LELSZ LAWSUIT HAS ALREADY TAKEN $15 MILLION IN TEXAS FROM THE SCHOOLS. BOTH COMMUNITY AND SCHOOL PLACEMENTS NEED TO BE AVAILABLE. FOR MANY YEARS NOW IT HAS BEEN AT THE EXPENSE OF THE SCHOOLS. THE COMMUNITY IS NOT THE MOST APPROPRIATE PLACE FOR THE PROFOUNDLY AND MANY, IF NOT MOST, OF THE SEVERELY RETARDED. THIS BILL'S PROPOSED FREEZE ON FUNDING TO LARGE INSTITUTIONS AND THE LIMIT ON THE FUNDING FOLLOWING INFLATION WILL CONTINUE TO TAKE FUNDING FROM OUR SCHOOLS CAUSING FURTHER REDUCTIONS OR CLOSINGS. NOT ONLY DOES IT TAKE AWAY FUNDING, IT HAS THE GALL TO TELL A PARENT AND PROFESSIONALS FAMILIAR WITH THE NEEDS OF MY SON THAT IF AVERSIVE BEHAVIOR INTERVENTION IS NEEDED MEDICAID WILL NOT PAY FOR IT. THIS BILL WOULD LIMIT PROGRAMS AND MAKE THESE DECISIONS ACROSS THE BROAD WITHOUT REGARD FOR INDIVIDUAL NEEDS.

THIS BILL IGNORES THE FACT THAT MEDICAID FUNDING FOR SUCH SERVICES ALREADY EXISTS THROUGH THE HOME AND COMMUNITY CARE WAIVER. THIS BILL DOES NOT PROVIDE FOR THE CHOICE OF THE BEST PLACEMENT FOR THE CHILD, WHICH SHOULD BE THE FIRST PRIORITY. IT HAS NOT BEEN PROVEN COMMUNITY CARE IS ANY LESS COSTLY THAN IN THE SCHOOLS.

THE MANY RESOURCES MY SON NEEDS ARE AVAILABLE ON CAMPUS WITHOUT HIM RIDING HOURS AND MILES TO REACH THEM. I HAVE HAD FIVE COMMUNITY DOCTORS USE EXCUSES TO REFUSE TO TREAT MY SON JUST IN THE LAST SIX MONTHES AND THAT WAS JUST FOR A BACK-UP DOCTOR OFF CAMPUS, THIS WAS NOT THE FIRST TIME I HAVE HAD THIS EXPERIENCE. WHY DO PEOPLE AUTOMATICALLY THINK THE COMMUNITY HAS TO BE BETTER FOR ALL THE RETARDED??? SEAN AND I HAVE BEEN THERE, "IT AIN'T SO!!!!!!!".

PLEASE DO NOT VOTE FOR OR SUPPORT THIS BILL! IN THIS "PROFESSIONAL" PARENT'S OPINION, IT WILL ONLY HURT THE PROFOUNDLY AND SEVERELY RETARDED! THE PARENTS DID NOT HAVE ANY INPUT ON THIS BILL, GIVE THE REAL PROFESSIONALS A CHANCE TO BE HEARD!!!!!

SINCERELY,
George E Bradley
GEORGE E. BRADLEY
1706 MIMOSA AVE.
PLANO, TEXAS 75074

Broward General Medical Center

1600 South Andrews Avenue
Fort Lauderdale, Florida 33316
305/355-4400

March 17, 1988

Ms. Laura Wilcox
Hearing Administrator
U.S. Senate
Committee on Finance,
Room SD-205
Dirksen Senate Ofc. Bldg.
Washington, D.C. 20510

Re: S.1673, The Medicaid Home and Community
Quality Services Act of 1987

Dear Ms. Wilcox:

I write in wholehearted support of S.1673, The Medicaid Home and Community Services Act of 1987. Across Florida, over 10,000 families need the help this Act could provide. Through its emphasis on using Medicaid funds for services such as respite care, small residential family homes, foster family homes, and community living facilities, S.1673 could be the most far-reaching legislation for the handicapped since PL94-142, the Education for All Handicapped Act. Services which help families keep their children at home for as long as possible are both humane and cost effective.

However, I take issue with the wording of the size limitations section of the Act. While smaller, more normalized settings should be encouraged, exceptions or waivers must be available for facilities serving severely/profoundly retarded children or adults who are also very medically fragile. These people are not best served in a small 4-15 bed house. The extensive medical equipment, therapy needs, day program requirements, and staff training required to adequately serve these children and adults are too expensive and too complex to be replicated in many small settings. I fear that attempts to do so would result in inadequate care or a total lack of availability of out of home placement for these people who need it the most.

In short, I SUPPORT S.1673, The Medicaid Home and Community Act WITH THE ADDITION of a waiver, exception, or separate set of limits for severely/profoundly retarded children and adults who are also medically fragile.

Sincerely yours,

Susan M. Widmayer

Susan M. Widmayer, Ph.D., Director
Children's Diagnostic and Treatment
Center of South Florida
Regional Perinatal Intensive Care Center

SMW/nr

A Facility of
North Broward
Hospital District

To: Senate Finance Subcommittee on Health, Washington, D.C.
Re: S. 1673, the Medicaid Home and Community Quality Services
Act ot 1987

Dear Sirs,
We are the parents of a pretty 15 year old profoundly retarded, severely physically handicapped, blind daughter named Christina. It is with more than casual interest that we comment on S.1673. Your proposal to cut funds to group homes with more than 15 clients can only be regarded as another example of government and politicians having noble intentions, but being far removed from the way things really are.
Our daughter requires the care of skilled professionals of the type which can only be found in large (I hesitate to use the word) institutions. Do not think that it was easy for us to decide to place our daughter in an institution. It never entered our minds and we rejected the very idea when she was smaller and we could take care of her.
We have been waiting for 2 years for an opening for Christina in a large group home, the type which you are planning to reduce funds for. Our family is under severe physical, mental and emotional stress from the constant care needed by our daughter, but the chance of placing her into a fine ICFMR facility, which is the only type group home that is able to serve her multiple needs, is very slim. Our daughter can not be served in a small group home due to her many disabilities.

We are appalled that you,as politicians are cutting funds again in places where they are neededmost, and where the demand for qualified residential facilities far exceeds the supply. Hundreds of families in Southern Florida alone are looking to only 2 or 3 such larger quality group homes for possible admittance for their children with pracitcally no hope for relief. With waiting lists that are years long parents become desperate. If you care about the stability of the American Family you must expand, not reduce funds to such homes.
We pray that your committee members will not forget the profoundly disabled minority in your hearings on this issue so that they and their families will also get a fair break in life, finally.

Thank you very much.

Sincerely,
Barry Carroll
Margarete Carroll
Barry and Margarete Carroll

MARCH 20, 1988

THE FINANCE COMMITTEE,

AS THE SINGLE PARENT OF A FIFTEEN YEAR OLD PROFOUNDLY RETARDED SON, I HAVE GREAT CONCERN ABOUT HB 3454/SB 1673, THE MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT OF 1987. MY SON LIVES AT FORT WORTH STATE SCHOOL AND THAT IS THE NEXT BEST PLACE FOR HIM. HOME WOULD BE THE BEST IF MY HEALTH STOOD THE STRAIN BETTER, I PRAY TO GOD THAT IT COULD. THIS BILL WOULD TREAT ALL DISABILITIES THE SAME MENTAL VS PHYSICAL, I WOULD GLADLY EXCHANGE MY SON'S MENTAL LIMITATION OF A TEN MONTH BABY AND MANY HEALTH PROBLEMS FOR ANY PHYSICAL LIMIT. THERE ARE SO MANY WAYS TO OVERCOME OR HELP A PHYSICAL LIMITATION BUT A MENTAL LIMITATION CAN ONLY GO SO FAR. WHEN I WAS TOLD MY SON HAD BRAIN DAMAGE AND THEY WERE NOT SURE WHETHER IT WOULD AFFECT HIM MENTALLY OR PHYSICALLY I PRAYED FOR IT TO BE PHYSICAL, BUT HE AND I WERE NOT SO LUCKY. MEDICAID IS ALREADY STRAINED, BY ADDING TO THE LIST OF ELIGIBLES IT WILL INCREASE THE COST BY MILLIONS EVEN IF IT ONLY PAYS A SMALL AMOUNT PER PERSON.

THIS BILL WOULD UNDERMINE THE ALREADY STRAINED STATE SCHOOL SYSTEM. THE LELSZ LAWSUIT HAS ALREADY TAKEN $15 MILLION IN TEXAS FROM THE SCHOOLS. WE NEED BOTH COMMUNITY AND SCHOOL PLACEMENTS AVAILABLE. FOR MANY YEARS NOW IT HAS BEEN AT THE EXPENSE OF THE SCHOOLS. THE COMMUNITY IS NOT THE MOST APPROPRIATE PLACE FOR THE PROFOUNDLY AND MANY, IF NOT MOST, OF THE SEVERELY RETARDED. THIS BILL'S PROPOSED FREEZE ON FUNDING TO LARGE INSTITUTIONS AND THE LIMIT ON THE FUNDING FOLLOWING INFLATION WILL CONTINUE TO TAKE FUNDING FROM OUR SCHOOLS CAUSING FURTHER REDUCTIONS OR CLOSINGS. NOT ONLY DOES IT TAKE AWAY FUNDING, IT HAS THE GALL TO TELL A PARENT AND PROFESSIONALS FAMILIAR WITH THE NEEDS OF MY SON THAT IF AVERSIVE BEHAVIOR INTERVENTION IS NEEDED MEDICAID WILL NOT PAY FOR IT. THIS BILL WOULD LIMIT PROGRAMS AND MAKE THESE DECISIONS ACROSS THE BROAD WITHOUT REGARD FOR INDIVIDUAL NEEDS.

THIS BILL IGNORES THE FACT THAT MEDICAID FUNDING FOR SUCH SERVICES ALREADY EXISTS THROUGH THE HOME AND COMMUNITY CARE WAIVER. THIS BILL DOES NOT PROVIDE FOR THE CHOICE OF THE BEST PLACEMENT FOR THE CHILD, WHICH SHOULD BE THE FIRST PRIORITY. IT HAS NOT BEEN PROVEN COMMUNITY CARE IS ANY LESS COSTLY THAN IN THE SCHOOLS.

THE MANY RESOURCES MY SON NEEDS ARE AVAILABLE ON CAMPUS WITHOUT HIM RIDING HOURS AND MILES TO REACH THEM. I HAVE HAD FIVE COMMUNITY DOCTORS USE EXCUSES TO REFUSE TO TREAT MY SON JUST IN THE LAST SIX MONTHES AND THAT WAS JUST FOR A BACK-UP DOCTOR OFF CAMPUS, THIS WAS NOT THE FIRST TIME I HAVE HAD THIS EXPERIENCE. WHY DO PEOPLE AUTOMATICALLY THINK THE COMMUNITY HAS TO BE BETTER FOR ALL THE RETARDED??? SEAN AND I HAVE BEEN THERE, "it ain't so!!!!!!".

PLEASE DO NOT VOTE FOR OR SUPPORT THIS BILL! IN THIS "PROFESSIONAL" PARENT'S OPINION, IT WILL ONLY HURT THE PROFOUNDLY AND SEVERELY RETARDED! THE PARENTS DID NOT HAVE ANY INPUT ON THIS BILL, GIVE THE REAL PROFESSIONALS A CHANCE TO BE HEARD!!!!!

SINCERELY,
Evelyn Cherry
EVELYN CHERRY
2038 MILL CREEK
GARLAND, TEXAS 75042

TESTIMONY

To: U.S. SENATE FINANCE SUBCOMMITTEE ON HEALTH, SENATOR GEORGE J. MITCHELL, CHAIRMAN

Subject: MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT - SENATE BILL 1673

Date of Hearing: March 22, 1988
Date written testimony submitted: April 15, 1988

My name is Judy Craig. My husband and I live at 5123 Mitchell-Saxon Road, Fort Worth, Texas 76140. Our phone number is (817) 478-5555. Jack and I are the parents of a profoundly retarded son, who is a resident of Fort Worth State School, Fort Worth, Texas. On January 20, 1988, we celebrated his birthday for the thirtieth time although he is less than a year old mentally.

Our son, Joe Bob, has an IQ of 5. He lived at home with us for 21 years. The first eight of those 21 years he had no training except what we gave him as a loving family. He has a brother three years older than himself and a neiphew. Joe Bob has touched all our lives, and we love him dearly.

It was only through our own intense search that we have been successful in securing services for Joe Bob. Therefore, we are skeptical of the claims of S.1673 to provide a wide array of services to fit the needs of a broad range of disabled persons. Our own experience has taught us that promises of something for everyone usually allows some to "fall through the cracks."

In the beginning we were told our son did not meet the criteria for special education or training programs for mentally retarded persons. They were expected to be toilet trained. In 1966, because I refused to give up, we did secure services, and Joe Bob began day classes at the Child Study Center in Fort Worth. At first, we had to pay tuition and provide transportation at our own cost. When federal funds became available in the early seventies for day training for the profoundly retarded, we thought it was wonderful that tuition was provided and we were given a transportation re-imbursement. Later, we learned that good things don't always last. Public Law 94-142 was supposed to guarantee a free education to all children regardless of the nature or degree of their handicap. It sounded good, but the result was that we received a letter from the Child Study Center stating they would no longer offer day training to our son and that we should contact our local public school district for educational services. At that time, the public school was not prepared to provide services for our son. The school district had the money, but it was up to us, again, to make a personal search for services.

Fort Worth State School provided day training for Joe Bob three years as well as respite services. In July, 1979, we decided to place Joe Bob on-campus as a resident.

This was a good decision because within a year the population of Fort Worth State School grew to the point that there were no more respite beds or day training placements. It was also a good decision because the school offers the kind of around-the-clock care and training Joe Bob needs. He needs assistance to feed himself; he is not toilet trained; he has difficulty walking; and he has little or no concept of danger. We bring him home for visits on weekends and holidays, but he is always happy to see his friends when he returns to school. The quality of care and training he is receiving is very satisfactory to us.

It is very important to us that Fort Worth State School receive the funding needed to continue to maintain its present services. Litigation and legislation seem to be constantly attempting to interfere with this process, however. Our population has been reduced to satisfy court requirements--from 490 in 1980 to 336 in 1988. Now, legislation threatens our federal funding. Around 80 percent of Fort Worth State School's budget is met with Medicaid funding. If S.1673 is enacted and the rate of inflation over the next ten years doesn't exceed 6 percent, as is being predicted, Fort Worth State School will lose 50 percent or more of its funding.

S.1673 discriminates against institutions such as Fort Worth State School. There is no cap proposed for smaller facilities. The bill also discriminates against persons like our son who cannot become productive. I don't see how (z)Specialized Vocational Services on page 10 would be of any benefit to our son.

We realize that services for the potentially productive handicapped persons need to be expanded, but we are appalled that anyone feels it is necessary to rob our son and other vulnerable persons of their security. We believe our son and others like him have the right to their own special pursuit of happiness. And, the best place for this is a large institution with the capability for concentrating expertise in many fields.

We simply want all anti-institution provisions to be removed from this bill. We've done the best we could for our son, and we will continue to do so. Don't cause our work to be in vain.

Jack and Judy Craig

4-15-88

Volunteer Services Council
for
FORT WORTH STATE SCHOOL
5000 Campus Drive
Fort Worth, Texas 76119

NOTE: I have been volunteering
for about five years since I
quit working outside the home.
My contribution is equivalent
to more than a year of full-time
employment.

March 21, 1988

Mrs. Judy Craig
5123 Mitchell-Saxon
Fort Worth, Texas 76140

Mrs. Craig:

As we prepare for the Eleventh Annual Volunteer Recognition Program on April 21, we find you have earned a total of 2,290 hours of volunteer service throughout December 1987. If you have earned additional hours we may not be aware of, please call the Volunteer Services office.

As a part of the Recognition Program we honor those who have contributed their time to Fort Worth State School with a presentation of a volunteer service pin. Enclosed is a complimentary ticket, so you may attend as a dinner guest of the Volunteer Services Council. If you wish to bring a guest or a member of your family with you for dinner, tickets are available for $9.00 each. In either case, please call our office at 534-4831, extension 283, with your reservation on or before April 15, 1988.

We look forward to seeing you and letting you know how much we appreciate all you do for Fort Worth State School.

Sincerely,

Frank L Breedlove
Frank L. Breedlove
Chairman
Volunteer Services Council

Jedd Blessing
Jedd Blessing
Acting Director
Volunteer Services
Public Information

FORT WORTH STATE SCHOOL
FACT SHEET
FEBRUARY 5, 1987

Fort Worth State School

Operated by the Texas Department of Mental Health and Mental Retardation
Service area - Tarrant and Dallas counties
Staff of 830, over 700 clients
Current annual budget $15.6 million
Philosophy summary:

- All client services provided in the least restrictive environment available consistent with developmental needs.
- All clients are capable of learning regardless of present developmental level.

Client characteristics:

- Male - 59 percent, female - 41 percent
- 20 years old and under - 46 percent, over 20 years old - 54 percent
- 76 percent fall within range of severely to profoundly retarded
- 50 percent have convulsive disorders
- 48 percent are mobility impaired

Residential Programs

Main Campus

- Opened in 1976
- Situated on approximately 270 acres
- Provides therapeutic training including physical and occupational therapy, educational and vocational programs, medical and dental services, religion and recreation

Community

- Started in 1975
- Serving adults, adolescents, juvenile offenders, autistic
- Group homes, contracted group homes, developmental foster care

Non-Residential Programs

Started in 1974
Help delay or prevent residential admissions
Programs include:

- Before/after school day care
- Family counseling unit
- Early Childhood Intervention
- Summer camps
- Respite services
- Integrated preschool
- Sheltered workshops

Public Committees

Volunteer Services Council - A group of community volunteers dedicated to enriching the lives of FWSS clients and to keeping the metroplex informed of school goals, activities, needs and accomplishments.
Chairperson: Frank Breedlove (214) 352-2663

Parents Association - Educational organization with the purpose of promoting the welfare of the clients of FWSS.
Chairperson: Judy Craig (817)478-6556

Public Responsibility Committee - Tarrant and Dallas county residents charged with protecting the rights of FWSS clients. Receives and independently investigates complaints.
Chairperson: Dr. James Allen (817) 284-9251

Citizens Advisory Committee - Group of independent citizens responsible for advising the administration and for providing communication liaison between the school and the Dallas/Tarrant County communities.
Chairperson: Dr. Donald Peterson (817) 877-1021

April 12, 1988

Committee on Finance,
United States Senate,
205 Dirksen Building,
Washington, D.C. 20510

Gentlemen:

I am opposed to Senate Bill #1673 the "Medicaid Home and Quality Services Act of 1987" introduced by Senator Chaffee of Rhode Island.

Senator Chaffee says that his bill offers many options in residential care for the developmentally disabled. Placing an immediate"freeze" on Federal Medicaid funding to all larger facilities (over 15 beds), as set forth in the bill, will force these facilities to close. It follows that sub-standard care will result for those left in these facilities until such time as they close. Community living facilities would be exempt from such a "freeze". This is discrimination against the residents of the larger facilities.

If Senate Bill #1673 is passed, the government will determine where our children, who now reside in the larger facilities for the retarded, will live, regardless of their parents wishes. Should parents be denied the final say in their children's future?

The bill fails to recognize the fundamental right of every person who now resides in one of the larger institutions (over 15 beds) to choose his place of residence.

Freedom of choice is a constitutional right giving to persons,parents, guardians and other authorized persons, the right to choose a place of residence that best suits their needs.

Parents had no in-put into Senate Bill #1673. Even though they have a better knowledge of the needs of their children, they were excluded from any decision making on the bill. Professionals cannot possibly know what parents look for and hope to find in the facilities where their child will, perhaps, spend the rest of his life.

My 28 year old son, the youngest of 8, was cared for at home until almost 4 years ago. He is cerebral palsied and retarded. He requires total care. Due to our age and health, my husband and I looked for alternate placement. As he is medically fragile, we were concerned that his health be closely supervised. He is now at Brenham State School. He has 24 hour nursing care and a doctor on call. He did not have this at home. He has adjusted well, is gaining weight and is more independent. To move him to another facility, if the state school were to close, would not be good.

A concerned parent,
Mrs Leo J Dekkers
Mrs. Leo J. Dekkers

April 7, 1988

Laura Wilcox, Hearing Administrator
Committee on Finance
Dirksen Senate Office Building, SD-205
Washington, DC 20510

Dear Ms. Laura Wilcox,

I am writing in support of "The Medicaid Home and Community Quality Services Act of 1987." I am asking for your support of Senate Bill 1673 and its companion bill House Resolution 3454.

"The Medicaid Home and Community Quality Services Act of 1987" is the most important legislation for the disabled since P.L. 94-142. I am concerned that the strong opposition this bill is receiving is for monetary reasons only. The individuals and corporations who are protecting their investments in institutional housing do not realize they are affecting the lives of citizens with disabilities and their families.

Passage of this legislation would provide individual and family support services, vocational services, protection and advocacy services, and a mandate for adult services.

According to Webster's Dictionary, a family is defined as; a group composed of parents and children; a household group,... Without this legislation, persons with disabilities will not be able to continue to live at home. Persons with severe disabilities have a right to live, work, and recreate in the community in which they live.

As you know, the lobbying group against this legislation is protecting their welfare. Institutionalizing persons with severe disabilities, promotes poor role models, poor living conditions, over medicating, little community involvement, and overcrowding with under staffing.

Please do not let the powerful efforts of one lobbying group keep you from researching and supporting this legislation. As a teacher of persons with severe disabilities, I want to see the same opportunities provided the non-disabled provided to the disabled and their families.

Thank you for your time and consideration.

Sincerely,

Valerie Ditzler

Valerie Ditzler
712 W. Burlington
LaGrange, IL 60525
312-579-1759

DIOCESE OF ALEXANDRIA
4400 GARDNER HIGHWAY
P.O. BOX 7417
ALEXANDRIA, LOUISIANA 71306
(318) 445-2401

MODERATOR OF
THE CURIA

March 9, 1988

Ms. Laura Wilcox
Hearing Administrator
United States Senate Committee on Finance
Room SD-205, Dirksen Senate Office Building
Washington, D. C. 20510

Dear Ms. Wilcox:

I have the pleasure and reward of serving on the Board of Directors of a very fine residential facility for the mentally retarded. This effort was initially begun in 1954 with very little capital and a great deal of faith on the part of the founder, Bishop Charles P. Greco. Through his efforts and the support of many benefactors, the initial facility has now enlarged to two programs, one in Alexandria and a sister program in Shreveport, Louisiana, serving a total of 336 mentally retarded. Through the support of the medicaid program, care has improved to a point of excellence that is recognized by all persons in the field of mental retardation.

Unfortunately, we now face a threat of reduction in funding that would reduce drastically the numbers of retarded who could be served. Senator Chafee of Rhode Island has introduced a bill, S-1673: Medicaid Home and Community Quality Services Act of 1987, which in its present form can be disastrous to the majority of the residents in either of our two facilities, as well as the rest of the nation who require a full array of services and twenty-four hour care. This is not available in smaller community homes.

I recognize that there are different levels of retardation and different degrees of need. I wholeheartedly support the concept of deinstitutionalization where practical and feasible; at the same time, I recognize and am concerned that certain of our population require and will continue to require continuing care as is furnished in facilities with a full array of services.

S-1673 in its present form would freeze medicaid funding for larger facilities (16 beds plus) to the level of spending at the time of enactment into law, with no restrictions on levels of spending in the community of group home settings. An exception being that more funds would be made available to the larger facilities provided the CPI exceeded 6% in a given year. As the cost of services gradually increase, this alone could force states into reducing services or moving residents into living arrangements which would be unable to furnish immediate access to the services that their individual disabilities require if they are to receive proper care.

The in-put into this bill came from professionals without any parental say in its drafting I ask the Senate Finance Committee to hold a public hearing and invite representatives from parent groups to participate in such a hearing.

I ask such a hearing be held and the bill be amended to insure that those who require the total array of services found only in ICF/MR's be allowed to remain where they are, with the same level of funding afforded for those in community residences. Also, that the parents have the right to choose the living arrangement that they believe to be most appropriate for their child, provided the child is incapable of making his or her own decision.

It is my belief that there is a need for both community living for those who can adapt to and benefit from such an arrangement just as there is a need for larger ICF/MR's for those who cannot adapt to the community due to their lower level of mental ability and/or multiple physical handicaps. The latter must have the total array of services available only in larger facilities. Until the advocates of change introduce a bill that would not be restrictive to those who require such supervision and services available only in the larger facilities, I respectfully request that you oppose S-1673.

Sincerely yours,

Ronald Hoppe

Very Reverend Ronald C. Hoppe
Vicar General

RCH:pl

Testimony of
Jack T. Dulworth

to

The Senate Finance Committee
March 22, 1988

RE: SB-1673
'The Medicaid Home and Community Quality Services Act of 1987'

Mr. Chairman...Honorable committee members.

My name is Jack Dulworth. Professionally, I am a businessman in Houston, Texas. My experience concerning mental retardation comes from the following:

1. I am the father of six children, one of whom is a profoundly mentally retarded daughter. Elissa Marie is 28 years old and a resident of Brenham State School for the Retarded, Brenham, TX.

2. I am on the Board of Governors of the Center for the Retarded, Inc., a private, nonprofit United Way agency that provides education, vocational training and residential services to mentally retarded persons in Houston.

   I also am a member of the Board of Trustees of the Foundation for the Retarded, a fund-raising organization that supports capital improvements of the Center for the Retarded. This organization also supports public education programs about mental retardation.

3. I was appointed to the President's Committee on Mental Retardation in 1987.

Today I speak on behalf of:

- the *Foundation for the Retarded*, Houston, Texas;
- the 1,000 parents whose children attend or are residents of the *Center for the Retarded, Inc.*, Houston, Texas;
- parents whose children attend state schools in Texas;
- and, at the request of Matthew J. Guglielma of the *California Association of State Hospitals - Parent Council for the Retarded*, I speak for that group as well.

As we understand the purpose of SB-1673, its objective is to encourage a greater variety of community and family support services for mentally retarded persons.

We have no quarrel with that goal. As advocates for the mentally retarded and their families, we certainly support anything that gives them a wider choice of services.

HOWEVER...SB-1673 does NOT expand choices. To the contrary, it restricts the choices for residential services.

As the bill now is written, it will freeze Medicaid assistance at current levels for individuals living in facilities of 16 beds or more. Only individuals who move into facilities of less than 16 beds will be eligible for future funding. If passed, it will eventually eliminate services currently provided by State schools and larger private residential facilities.

The bill requires individuals in larger facilities to begin moving into smaller facilities in order to keep their Medicaid assistance.

Ladies and gentlemen, the Chaffee Bill does nothing but shift Medicaid funding from a variety of residential facilities to small group homes. Is this wise?

Over the course of time...through sheer power of its funding bias... the Chaffee bill will force many larger public and private facilities to close their doors. Not because the demand for their services isn't there... but strictly because individuals who need those services will be denied Medicaid eligibility. It's a very subtle form of denying freedom of choice.

It has never been proven that smaller homes are indeed better for mentally retarded persons. We don't believe it will ever be proven.

Let me offer my own situation as an examole.

As I mentioned, I am a board member of Center for the Retarded, Inc.

As a board member, I would have no problem getting my mentally retarded daughter accepted in any of the residential facilities operated by CRI.

One of those facilities is Cullen Residence Hall. It has 210 moderately retarded adult residents. They work in the community or train in the nearby sheltered workshop. They come and go freely. They have a wide choice of social activities and field trips to opera, symphony, sporting events, movies, restaurants, picnics, dude ranches and other enjoyable recreation. They have a snack bar, drug store, bank, infirmary, cafeteria and counseling services on site.

But my daughter doesn't live there.

If I wanted, I could have my daughter live in one of the Center's group homes. CRI operates four of them. These are the kind of homes favored by the Chaffee bill. They are located in residential neighborhoods, and the residents live there with house parents. They carpool or take busses to their daily jobs and training activities. They share the chores of maintaining the household.

But my daughter doesn't live in one of these group homes, either.

We now have a new facility under development. It's a 300-acre rural community designed exclusively for mentally retarded persons. It will have 12 group homes, each of which will house 8 residents plus house parents. An on-site agribusiness complex will provide paying jobs for these residents. As a major fund-raiser and donor to this facility, I certainly could get my daughter accepted there.

But she won't live there, either.

Instead, my daughter lives at Brenham State School for the Retarded, 120 miles away from home.

Why?

Because her level of retardation and functioning are so low that she is not suited to the less restricted life-style of the other facilities available to me.

Elissa is the 3rd of our 6 children. Now 28 years old, she has a mental age of 6 months and an I.Q. of 18 months. Her problems include:

- Partially crippled.
- No judgment regarding safety.

- Has a condition called "PICA", meaning she cannot distinguish between edible and non-edible objects. She will eat paint, paper, etc.
- She will walk away at any time.
- She's hyperactive -- up and down all night long.
- She needs constant supervision and custodial care.
- She needs constant medication.
- She needs diet supervision
- She has seizures.

When Elissa still lived at home -- and she did until age 17 -- I had to install a six-foot chain link fence around our entire house and make certain the gates were always locked. I often reflect upon how my wife kept her sanity during those years.

One of the greatest things that happened to us was having Elissa admitted to the Brenham State School as a permanent resident at age 17. The facilities are magnificent and this great institution is one of only 35 accredited.

As a parent, I had to face reality. I had to make the choice that was in the best interests of my daughter, my family, and my community.

But the important thing, ladies and gentlemen, is that I had a choice. I wasn't limited to only a state school...or only a medium size high-rise...or only a group home. I was able to choose the type of facility that best fit the need.

Edward Zigler, Sterling Professor of Psychology at Yale University, is a recognized authority in the field of mental retardation. In a speech before the American Psychological Association, Zigler said:

> "An optimal social policy for the retarded would provide real choices. Available options should range from family care to placement in large institutions, depending on the characteristics and abilities of particular retarded individuals and their families...These issues are extremely complex ones and cannot be resolved by taking refuge in the still highly questionable philosophy of normalization."

As a parent, I understand how important it is to have choices. For 40 years, the volunteers, parents and professionals of the Center for the Retarded have worked hard to develop a range of programs and facilities. We recognize that no one program or facility is appropriate to all mentally retarded persons.

In many ways, the needs of mentally retarded citizens are similar to the needs of senior citizens.

Some senior citizens like to live around their peers in Florida condominiums. Others retire to private homes in the suburbs. Some remain in apartments in the heart of the city. And others, because of health reasons, need the security and support of nursing homes.

To give preferential funding to mentally retarded persons who live in small group homes is the equivalent of limiting Social Security benefits to just those senior citizens who live in houses in the suburbs. It just doesn't make sense.

What we propose therefore is NOT that you kill SB-1673...but rather that you change the passages which favor one form of life-style over another. We recommend that you let the funding follow the needs and the choices of the individuals served.

By changing the funding formula, you would allow the free market principle to work. Those facilities that don't meet the needs with quality service would fall by the wayside. On the other hand, those that do best meet the needs of each community would prosper and grow.

Please change SB-1673 to encourage the development of choices.

Thank you.

* * * * *

ELLISVILLE STATE SCHOOL PARENTS ASSOCIATION
ELLISVILLE, MISSISSIPPI
39437

April 8, 1988

Committee on Finance
United States Senate
205 Dirksen Building
Washington, D. C. 20510

Gentlemen:

As relatives and friends of the mentally retarded in our state, we would like to express our opinion in regard to Senate Bill No. S1673, the Medicaid HOme and Community Quality Services Act of 1987.

We believe this bill, if passed, would have a negative effect on the services presently available to our severely handicapped citizens.

You cannot lump all of the severely handicapped and disabled into one category, nor is it realistic to believe that all of our handicapped, and particularly, the mentally retarded will be able to achieve independent living goals.

The money to provide all the services necessary for the severely handicapped in a community setting will simply not be available. Much progress has been made in the field of mental health and mental retardation in the past few years, but unless the funds continue to be available in this same manner, we feel that we will be back where we started and the losers in this battle are going to be the mentally ill and retarded in our country.

We urge you to give this bill serious consideration before making any changes in the existing system.

Sincerely yours,

Jim Crawford

James T. Crawford
President, Parents Assn.
Ellisville State School

March 22, 1988

COMMITTEE ON FINANCE
United State Senate
205 Dirksen Building
Washington, D.C. 20510

Finance Subcommittee on Health

RE: S.1673 THE MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT OF 1987.

Dear Senator:

I have three beautiful children. I am writing to you on behalf of my middle child, Jordan, who is five and one half years old.

Shortly after Jordan was born, after a wonderful healthly pregnancy, and a very easy delivery, we realized "something" was not right. He just did not seem to be progressing or changing in any way, from his neonatal behavior. At 3 months, he couldn't lift his head. We went to our pediatrician who assured us that all babies mature at different rates. At 6 months nothing had changed. My husband David and I had gone from mildly apprehensive to very distraught. We went to a pediatric neurologist with Jordan and subsequently, he was tested for every known neurological disease. Every test came back "normal". We went up to Boston Childrens Hospital, where he was retested, and we came away with no answers, no diagnosis, no prognosis.

Our beautiful son was one year old already, developmentally still a babe in arms. We were determined to do something to help him. We tried conventional physiotherapy and speech therapy. We tried some unconventional therapies, hoping that we could make a difference. Our schedule with Jordan was intensive, demanding, and exhausting. We enlisted the help of others, and hired an attendant to help with his care. Every waking moment was centered on this sweet child, not only out of love, but also out of necessity because he could not do for himself.

It took it's toll; our daughter, 5 at the time, deserved our attention but our attention was focused on Jordan. My husband was so depressed and overwhelmed by our tragedy, he could not work. I was a bundle of nerves and we were both suffering physically. Financially we were drained, thankfully our parents could help somewhat. Jordan, at two years old was still functioning below a 3 month old level. We made a very painful decision; we couldn't sacrfice three vital lives for the sake of our son, who could never benefit from all our love, care and devotion. We would place Jordan in a permanent residential facility.

I was in for another shock, as if I hadn't been through enough already. I called HRS (Health and Rehabilitative Services) and other agencies for the mentally retarded inquiring about facilities. They were hostile, secretive and almost antagonistic. They refused to furnish me with a list of suitable residential facilities! The explanation was, that they believed the best place for my son was at home. It didn't matter what happened to the rest of the family, or that Jordan didn't even know he was part of a family. Unless, he was abused, or I would make him a ward of the state, he did not fit the "criteria" for permanent placement.

It was a terrible time. Just by luck, through a cousin in New York who was speaking with a social worker there, we were sent a hand written list of facilities in Florida. The list consisted of a mere eight, six of the eight were inadequate for my son's care. (They were group homes) One was Kradle Kare in Maitland, a suburb of Orlando, 4 1/2 hours driving time from our home.

We were very impressed with Kradle Kare. They only have fifty children, all of whom are non-ambulatory. Most of the children are profoundly retarded and severely medically fragile, requiring tube feeding, respirators, constant intensive nursing care etc. Registered nurses staff the facility 24 hours a day, and they are extremely caring and sensitive people. All of these children are incapable of doing anything for themselves, just like Jordan.

Sir, the bill you have introduced (S.1673) is no doubt carefully researched and certainly your heart is in the right place. However, please do not discriminate against the meekest and weakest among us - those individuals like Jordan who have no voice and never will. To freeze funds (Section 4 - Limitations on Payments for Services Provided in Large Facilities.) in the type of facility where my son needs to reside would be catastrophic! A smaller facility (6-15 beds) may sound more home-like and be more pleasing to the eye, but how could it be financially feasible given the type of intensive nursing care profoundly retarded and severely handicapped individuals require?

Staffing, equipment and schooling (eg. done on the grounds at Kradle Kare, for those who can't be moved) could not be duplicated at the current excellent standard.

My son, at 5 1/2 years old doesn't recognize me. He doesn't "know" anyone, even those who care for him every day! He must be spoonfed pureed food every meal. He cannot walk, talk, or crawl. He can not sit by himself nor can he roll over when he's lying down.

Sir, do you really think he would benefit from being in a smaller institution? Certainly, for the mild-moderately retarded people capable of living with supervision, working in sheltered work shops, the scenario you are projecting is a wonderful step forward. I celebrate this bill on their behalf. But, do not take one step forward while taking two steps back, forgetting that there are those who are dependent completely and irreversibily dependent on others, for the rest of their lives. Freezing their funds seems punitive without cause. In fact, more funds are needed, to open more 50 bed facilities. Waiting lists are very long. Family relationships and patience wear thin waiting for placement for children such as mine. No family should ever be denied placement for their child if thats the parent's decision, and it can only be the parent's decision. Social workers and legislators may read many text books and studies, but they've never walked in my shoes. No one asks for tragedy, and no one should have the power to determine the fate of anothers tragedy.

This government has determined that life is to be prolonged and heroic measures taken to sustain life. But, that clause in your bill which seeks to limit the funds for those very ones who are saved, is clearly at odds with this philosophy. You can't burn the candle at both ends.

Please revise this oversight, in the Medicaid Home and Community Quality Services Act of 1987, and seek to improve the quality and care for all handicapped people, including the small percentage like my sweet Jordan.

Thank you for your kind attention. I look forward to your reply.

Sincerely,

LENI ENGELS
DAVID I. ENGELS
4812 Garfield Street
Hollywood, Florida 33021
(305) 981-4141

Apr.16,1988

Miss Laura Wilcox
Hearing Administrator
U.S.Senate,Commission on Finance
205 Derksen Sen.Office Bldg.
Washington,DC 20510

Dear Miss Wilcox:

This in in lieu of a personal report to the Senate Committee on Finance in regard to the Medicaid Home and Community Quality Services Act (S1673).

We feel to have a unique case in support of this bill.

Our son,Steve has been in an institution for 1¼ years,the (in 1985) $ 51,000/year Milwaukee County Medical Complex,where doctors did not know that Steve's kind of client needs structured daily activity to keep their behavoir satisfactory.Instead they drugged him and others.He became incontinent, drooled,developed an awkward gait and arm posture,and was on the way to become a living vegetable.

Because there was no Federal money for the services he needed, we had to fight tooth and nail to get a waiver for the proper daily activity at the Ranch in Menomonee Falls,WI.

Now he is greatly improved,his urinary and bowl functions normal again,is on no drugs,and lives at home.The cost of the Ranch program is $ 15,000/yr.,which includes transportation.

Because of growing waiting lists for community based services,there is talk about reducing the present service level.In our case,we parents (66 & 58 years old) could not bear the added load and Steve would fall back into the drug poisonig of the institutions.

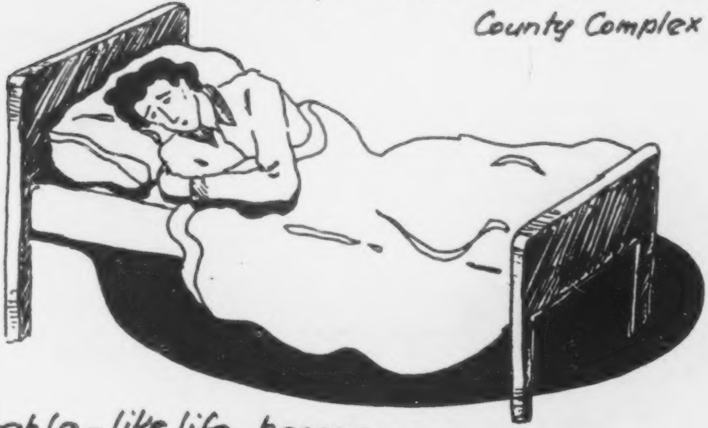
Therefore we request that the Senators pass this bill.

Sincerely,
Mathew Eszes

Mathew Eszes,2435 N. 64 St.,Wauwatosa,WI 53213

P.S.: Please,observe the attached illustrated condensation
of the aboves.

Steve, when he was at the Milwaukee County Complex



Vegetable-like life, because instead of structured daily activity he was drugged

Cost County Med. Comp.	$ 51,000/year
nursing homes over	$ 30,000/yr.
State Centers	$ 78,000/yr.

or

$ 15,000/yr for loving structured COP① activity at the Ranch②, with no drugs, and living at home

① Community Option Program

② Daytime activity center in Menomonee Falls, WI

Steve these days, ready for the Ranch van

April 8, 1988

Testimony of Harold L. Flanagan concerning S. 1673: Medicaid, Home and Community Quality Services Act.

My name is Harold L. Flanagan, 7103 Gateway Blvd., District Heights, MD 20747, father of a son who is mentally retarded in the severe and profound category. He has lived in the second largest State operated mentally retarded institution in the State of Maryland for fourteen years, interrupted by two probationary periods in Community Living programs.

I oppose S. 1673 as presently written because it transposes a problem rather than correcting it. The original bill prepared by Senator Chafee was developed because the Federal reimbursement for health services rendered favored institutions over Community Living programs. The revised and present S. 1673 favors the Community Living program over the institutions. This is accomplished by placing CAPS and denying inflationary increases to the institutions while not placing such limitations on the reimbursements made to the Community Living programs.

With the remaining population in institutions as well as any new admissions in the severe and profoundly categories the cost of providing special services for these residents will be more expensive and reducing this needed care could lead to more undeserved horror stories about the care rendered to residents in institutions.

Another weakness of this bill is allocating to States the responsibility of overseeing the implementation of the provisions of the bill without Federal government direction and control. Past experience haa shown that when such a condition exists State funds available rather than the need that exists has been the determining factor in prescribing the surveillance needed.

As an individual who has been an advocate for the handicapped for many years, I know that both institutions and Community Living programs need Federal relief in the reimbursement for health services rendered, but I hope that the injustices cited can be corrected and not at the expense of either program before this bill is passed.

11 April 1988

COMMITTEE ON FINANCE
United States Senate
205 Dirksen Building
Washington, D.C. 20510

Finance Subcommittee on Health

RE: S.1673 - THE MEDICAID HOME AND COMMUNITY QUALITY SERVICES
ACT OF 1987

Dear Senator:

I am writing to you on behalf of our first born, Andrew, who is now 17 years old. From birth, Andy has been mentally retarded, diagnosed also as Microcephalic. I feel we did everything we possibly could for his welfare and benefit. When Andy was 2 1/2 years old, we enrolled him in the "New Hope" Center located in Cocoa, Florida. This program's basis was to establish a "patterning" in the brain which would eventually signal basic movements as we know them (i.e., crawling, sitting, standing, speech, etc.). For a year or so, we had to drive Andy from Palm Bay to Cocoa, return to our work location in Palm Bay, then pick him up once again at the end of the day and return home. We spent numerous hours driving (120 miles per day 5 times a week) as well as working with him. We used to have relatives and friends come by every evening during the week and 3 to 4 times on week-ends to help us pattern Andy. Eventually this took its toll on all of us and we reached a point where we were totally dedicated to Andy but we were also exhausted physically, mentally, and emotionally. And on top of that, extremely frustrated as Andy had not progressed the way New Hope had led us to believe he would. The Psychiatrist finally admitted he didn't believe the program would help in Andy's situation. Needless to say we stopped New Hope and made a decision to enroll Andy in the Easter Seals Program located in Melbourne. Everyone was much happier, including Andy, and we began to settle into a more normal family routine. In spite of everything, Andy did exceed the expectations of the

Doctors at Shands Teaching Hospital in Gainesville. They said he would never walk but he did at age 4 1/2. They told us he would never talk, but by age six you could carry on a conversation with Andy even though this was very limited, but he had a vocabulary of approximately 100 or so words. They also told us Andy would never be able to be potty trained - he was at age 5. Andy was also capable of aiding us when we dressed him and he was able to feed himself and drink from a cup by age 6. So as you can see, Andy progressed far beyond the hopes of the doctors. Each small achievement to a "normal" world was a major victory with Andy. He was a very happy child, he had no concerns and no worries - he laughed at everything. Yes, you are right - those with disabilities need help in achieving their fullest potential, but the needs of one may differ from the needs of another. If we had placed Andy into an institution at the time he was born, I believe we would have cheated ourselves and Andy at that time. We weren't prepared to give up yet. We had a battle to fight and we could see the victory!

But at age 7 disaster struck again. Andy had a stroke that wiped out his vocabulary and paralyzed his left side. He was no longer able to talk, walk, or run. Everything we had accomplished was wiped out in one foul swoop. All our dreams crashed in around us. We had nothing left to give and nothing left to hang on to. It was very difficult just live one day at a time much less plan anything for the future, but we knew eventually we would have to face the probability of Andy leaving us to live in a home other than ours. When Andy was 9 1/2 years old, that probability became a reality.

We took the wise advice of Andy's nuerologist and I gave birth to two more children, perfectly happy, normal and intelligent. Shanna is now 8 and Christopher is 6. But as we watched Shanna's growth and her maturing, she was beginning to mimic Andy in her sounds and movements. To Shanna, Andy was her example. After Andy's stroke, he never was our happy little boy again. He reached a level of frustration he couldn't understand. Why couldn't he do the things he so wanted his body to do? Eventually he was able to scoot around slightly on the floor but he was always irritable. And even though Andy was on phenobarbital and dilantin to control his seizures, he continued to have grand mal seizures. Shanna not only was frightened by these episodes (which occurred on a daily basis) and couldn't understand what Andy was doing, but she also thought she should react this way too. This is when we finally solicited the much needed help of HRS and thru their valiant efforts, they introduced us to the ideal home for Andy which was (and still is) Kradle Kare, located in Maitland, Florida approximately 3 hours from our residence. This home is only for mentally retarded and physically handicapped children who are non-ambulatory. It is a residential facility for 50 children, all of which require constant nursing care to some degree (i.e., seizures, respirators, tubal feedings, medications, blood pressure monitoring, medical surveillance, etc.). Dr. Carter makes rounds and observes/treats and hospitalizes the children as medically necessary. Since Andy's arrival at Kradle Kare, he has had his share of hospitalizations and does keep Dr. Carter on his toes (as he did us before he left). Two years ago Andy was admitted to the hospital because of pnuemonia, a disease he is very receptive to since his immunity level is so critically low. Because he started to cough up blood after his arrival, other tests were prescribed. It was then discovered Andy needed to have surgery to repair a hiatal hernia and also a procedure called Nissen Fundoplication was recommended to prevent further gastroesophagel reflux. What I am trying to point out is that even under careful monitoring and expert care, this condition went undetected for who knows how long because Andy couldn't tell anyone what was wrong. Because of all his medical problems and past complications, he would not be a good candidate for your program. Noteworthy of mentioning, I received a letter from Dr. Cavett who performed the above surgery and two of his comments stated: "As we were able to follow Andy so long after the surgical procedure we did not feel it was necessary to bring him in for specific post charge follow up as he is receiving such good care at Kradle Kare." And "Regarding you final question (addressed to us), we will be monitoring the gastric tube only through the nurses who are providing his care. Obviously, should he be able to take 100% of all necessary nutrition by mouth, then we will be able to remove the gastrostomy tube and, therefore, remove that aspect of management from his daily care." Especially after this incident, even though we always knew deep down, we were convinced Andy was in good hands. The nursing staff is top notch. They are always on top of Andy's condition and respondent to my questions concerning Andy. If Andy needs to see a specialist (i.e., Internist for thyroid problems, an Opthomologist to check his eyes and persistent eye infections, or a Dentist, etc.), when medically justified, an appointment is made and Andy is taken. Mr. Meier who runs the facility has always been up front and honest with us. From the beginning he never led us astray on false hopes. He always made it perfectly clear to us that should Andy ever become ambulatory or exceed their requirements in any way, other arrangements would commence to have Andy placed elsewhere. Almost on a daily basis, they have high school students who come in voluntarily to help feed the children and play with them, so they do get a little extra individual attention. They all truly care. it's not just "their job"!

For the children who are able to be transported back and forth to school, they attend Rosenwald, which is not too far from the home. This school is only for these "special" children, so there is no peer pressure, no snide remarks or jokes making fun of "the retards". It's a wonderful school specially dedicated to these children. When we did have Andy at home and he was attending regular public school, we experienced hurtful remarks from other "normal" children. And even if Andy couldn't understand what they said, we could and it hurt us deeply. There are also provisions for the children who are unable to attend school. There is a trailer complex at Kradle Kare where the children are taught on the homebound program. Andy has participated in both so with first-hand knowledge, we can attest to the fact that their goal first and foremost is in helping these children to achieve their utmost in the best and safest way possible. What parent in this situation could ask for more? Andy has been at Kradle Kare for 7 1/2 years now. He has his life and we have ours, and unless God performs a mighty miracle on his/our behalf (and believe me we do pray this way), he will never be free of his medical problems or be capable of caring for himself or anyone else. He is totally dependent upon others for every need, whether this be medical or just every day living. We plead with you not to discriminate against facilities such as Kradle Kare, as this is how it appears to us in the bill you have introduced (S.1673). It does not seem fair to freeze the funds (Section 4 - Limitations on Payments for Services Provided in Large Facilities) in places such as Kradle Kare that have provided a safe haven for our son for so many years as well as other children like Andy. Please don't misunderstand. We do applaud your efforts and what you are bringing to light, but what your bill is proposing is not the answer for everyone. We don't feel Andy would improve or be any better off being in a smaller facility. It would not provide him a better means of reaching his fullest potential. If you truly want to help the retarded and handicapped, you can't shut the doors on one and open the doors on another. More facilities like Kradle Kare would far outweigh the needs of many versus the needs of a few in a group home.

I implore you and your committee to tour Kradle Kare and show me one child who is capable of cooking for themselves, or show me one who can clean up after themselves, or even one who can make a bed. My goodness, these children are all confined to wheelchairs and/or beds. They will never fit the criteria of a group home. They will never be capable of vacuuming a rug much less learn how to even turn on a vacuum cleaner. They will never learn to keep the place up. These children must totally rely on others for their survival.

You say on one hand that "any number of disabilities has medical needs which must be met", and "That is recognized". And yet, on the other hand, it appears you fail to recognize that medical costs have escalated and will continue to do so year after year at a rate much higher than inflation if nothing is done to stop it. According to the Consumer Price Index last year, it increased 31.8%. Therefore, if medical costs continue to increase, yet you freeze funds for the institutions at current levels expecting them to operate at the same rate, these children are the ones who are going to suffer, and the sad thing about it, none of them can voice their opinion.

Ultimately something will have to give for things to remain status quo as you have proposed. One of the aspects of my job is budgeting Annual Operating Plans and Quarterly Budget Plans for a large company. In order to operate with frozen funds tells me that these children will have to receive less medical attention, or maybe it will be less supplies, or it could possibly be a reduction in staff (nursing or maintenance), or maybe it means there would be fewer beds available, etc. I think these are enough examples to get my point across. I'm all for you helping the disabled, but please don't do it at the expense of our son. As far as we're concerned, there aren't enough facilities like Kradle Kare in existence now to meet the needs of this State so I seriously doubt it is any better nationwide.

As for the many families who choose to keep their children at home, feeling that they don't want them stuffed away in an institution somewhere, obviously they are ignorant of these facilities and the special needs of these children because I once felt this way also; or their children may be far more advanced and capable of achieving much more than our son; or maybe this is their way of combating the untruthful guilt they must overcome as we once did - the sense of being a failure as a parent - be it Mother or be it Father. But regardless of the justifications involved, the "right" choice needs to be available whether it be at home, in a group home, or in an institution, and that is a choice we as parents have to make. It is not your decision, and unless you have walked in my shoes, I don't see how you can make that choice.

I feel we have been on both sides of the coin and I ask myself if I wouldn't be exuberant over your bill had Andy not suffered the stroke and my reply would undoubtedly and absolutely be "YES". But flipping the coin over to the other side and having experienced all life has dealt us, I feel threatened and endangered by your bill. I fear for the well being of our son.

It took us a long time to reach the decision to have Andy placed elsewhere. And as far as we're concerned, we will never regret or look upon it as a mistake but rather as a blessing! Open the doors and fight for ALL of these people - not just those who are capable of achieving and accomplishing in this life time. Please don't lose sight of the fact that there must be long-term care services that are medically oriented, and our child should not be punished if this is the best place for him to reside - nor should we be punished for making this choice.

We respectfully beseech and request your assistance in amending the Medicaid Home and Community Quality Services Act of 1987 to encompass ALL mentally retarded and physically handicapped people, one that promotes equality of care and services for ALL the disabled, from the severely/ profoundly to the mildly-moderately retarded and handicapped.

We are putting our faith in you to see that this is accomplished. We earnestly await your reply.

Sincerely,

Jean M. Florin
Barry A. Florin

Jean Florin
Barry Florin
P.O. Box 66
Grant, Florida 32949
(305) 723-5728

PLEASE INCLUDE THESE VIEWS IN THE PRINTED RECORD OF THE HEARING Pg.1/1

Date: April 9, 1988
Re: S.1673 Hearing

Committee on Finance
U.S. Senate
205 Dirksen Bldg.
Washington D.C. 20510

Dear Sirs,

As the parent of a child whose mental retardation is classified as "severe and profound," I call your attention to the following points regarding Sen. Chafee's Bill S.1673:

1. It is unlikely that money will be saved by closing larger institutions for the mentally handicapped and transferring these citizens to smaller facilities such as group homes. Many larger facilities are already in place; group homes would have to be purchased. In larger facilities, management is "on site;" in smaller group homes, management would be more of a concept than a reality. Larger facilities have classrooms within walking distance of living quarters; with smaller group homes, everyone has to be transported everywhere. The higher costs of purchasing group homes, managing them efficiently, and transporting residents to and from them daily makes them an unwise economic alternative to larger public and private facilities currently available.

2. S. 1673 stipulates that within five years, and regardless of their conditions, all retarded citizens should be trained and then transferred to smaller facilities. This idea may prove beneficial for some, but certainly not for all retarded citizens regardless of their conditions. My son, for example, is non-verbal and is not toilet-trained. Since he lived at home for 13 of his 16 years, I can say without reservation that he receives better care and is making more progress toward independence in a residential school setting than he did when he was living at home. The question is, What happens to him if he is not prepared for a smaller facility in five years?

The closing of larger facilities for the mentally retarded would mean a lower quality of life for my son and higher costs to the federal government. I urge you to vote against S. 1673 in its present form.

Sincerely,

Gene Flusche

Gene M. Flusche
11777 Parkmount Blvd.
Baton Rouge, LA 70816
(504) 925-5055

WENDELL H. FORD
KENTUCKY

COMMITTEES:
COMMERCE, SCIENCE AND TRANSPORTATION
ENERGY AND NATURAL RESOURCES
RULES AND ADMINISTRATION

United States Senate
WASHINGTON, DC 20510

March 24, 1988

Dear Mr. Chairman:

The Kentucky Association of Private Residential Resources and the Concerned Families of Hazelwood Hospital and other residental facilities in Kentucky, requested that I assist them in securing a witness slot at the March 22 hearings before the Subcommittee on Health on S. 1673. Due to the number of requests to testify received by the Committee, I understand that it was not possible to accommodate all interested individuals. I respectfully request that the testimony that would have been presented by this group be included in the hearing record, along with my letter, a copy of a letter from the Kentucky Cabinet for Human Resources, and an editorial by the Louisville Courier-Journal. I am enclosing five (5) copies of this testimony, as requested by your staff.

I strongly support what this legislation attempts to do, namely, provide additional services to our mentally retarded/disabled and provide additional funding to allow these individuals to remain in their own homes, where possible. However, I cannot support, and must actively oppose, the funding mechanism for this bill.

The CBO and the OMB both recognize that the savings created in the first years of this bill result from freezing funds to institutions, and the savings are overcome by the costs of the program in later years. While I support allowing families to keep their loved ones in their family homes, I cannot support it at the expense of those who find institutional care to be more appropriate. It is an unsupported assumption that institutions with less than 16 beds provide better quality or more appropriate care than larger institutions. In Kentucky, we have moved on several occasions to deinstitutionalize, and have found that for some, institutional care is often the most comprehensive, safe, and appropriate care.

This bill simply does not recognize efforts made in some states to actively deinstitutionalize the mentally retarded. In Kentucky, we have been in the forefront of trying to move these individuals into community-based care,

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LEXINGTON, KY 40504
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COVINGTON, KY 41011
(606) 491-7929

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OWENSBORO, KY 42301
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and we have had some success. But we also have found that institutions, when properly regulated, can provide the best care for some individuals.

While we have a good system for providing services for these individuals in Kentucky, I am concerned that under this bill, state officials who develop the required state plan will actually have the final say on where the mentally retarded will be placed. Although the bill provides that this decision will be made by an advocacy committee with individual and family input, it does not provide that families who wish to keep their loved ones at home will be able to do so as a matter of choice. Ultimately, the State must allocate the Medicaid dollars under the state plan.

I am also concerned that this legislation discriminates against some of the mentally retarded by denying the expanded services provided by this bill to those in institutions. Clearly, no matter how well-regulated and well-funded community-care might be, there will always be a need for institutional care. To deny the benefits of this bill to those most severely handicapped in institutions is cruel and unnecessary.

If we are truly dedicated to improving services for the mentally retarded, we should recognize that this will require significant funding, and we should provide the dollars to pay for those services for all of these individuals, without arbitrarily denying them to those in institutions. While the current budget deficit may not allow that at this time, we should not discriminate against those in institutions in order to pay for services for those in community-based care.

I appreciate your accommodation in this regard.

Sincerely,

Wendell

The Honorable Lloyd Bentsen
Chairman, Senate Finance Committee
United State Senate
Washington, D.C. 20510

cc: The Honorable George J. Mitchell

Enclosures

STATEMENT ON MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT

S. 1673

This statement is submitted by the Board of Directors on behalf of the membership of Friends of Evergreen, an organization formed to maintain a continuing relationship between the staff of Presbyterian Ministeries, Inc. and the parents, other next-of-kin or legal represenatives of the developmentally handicapped clients of the facilities owned and operated by Presbyterian Ministeries, a charitable organization.

Presbyterian Ministries, with headquarters in Bossier City, Louisiana, owns and operates various facilities in northern and central Louisiana, including the Evergreen Developmental Center, an intermediate care facility, near Minden Louisiana. This center is in a rural area on 467 acres. It has about 20 buildings, including dormitories for male and female clients, a central kitchen and cafeteria, medical offices, gymnasium, classrooms, chapel, animal barn, dairy, softball field, swimming pool and fish ponds. The center has a staff which includes social workers, health care workers, teachers and house parents. The facility presently has dormitory beds to accomodate approximately 244 clients.

In addition to Evergreen Developmental Center, Presbyterian Ministries owns and operates nineteen community based small facilities in northern and central Louisiana, consisting of group homes, independent living apartments and boarding houses. There facilities, none of which has more than six beds, presently are serving 131 clients. Both the Developmental Center and the community based facilities are licensed and certified by the state of Louisiana and receive state and federal funding under title XIX of the Social Security Act.

As parents or next-of-kin of developmentally disabled persons served by both a large institution and small community based facilities, we support the provisions of this bill that would expand funding of community based facilities and family support services for those individuals whose handicaps make it possible for them to best benefit from such services. However, we urge that these services not be utilized to force from larger intermediate care facilities those severely handicapped persons whose handicaps make institutional care the only desirable alternative.

Our major concern with the bill is the adverse effect that it would have in funding the services now afforded to severely handicapped persons by Evergreen Developmental Center, the intermediate care facility. This would result from the provisions in Section 4 of the bill that would cap funding for such institutions at present levels, with provision for escalation only if the cost-of-living increase in any year exceeds 6%, and then only by the percentage over 6%. Assuming continuation of current inflation rates, funding for intermediate care facilties would be reduced to half the current rates in fifteen years under this provision regardless of the number of handicapped persons who could be properly served only by such facilities. We consider this evidence of continuing anti-institution discrimination which was obvious in the earlier versions of this legislation.

What is needed is not Medicaid funds for either larger or smaller facilities, but sufficient funds to provide quality care in all settings. By imposing a cap on funds for institutional care, the proposed legislation has pitted against each other two groups of concerned parents - those whose children can be cared for properly only in larger facilities against those whose children's handicaps permit them to be served in smaller community based facilities. This is unfair to both groups. Neither is well served by those who urge the unrealistic dogma that all developmentally handicapped persons can best be cared for in small neighborhood facilities. Available options should range from family care to placement in larger institutions depending on the characteristics and abilities of each individual.

Those who would impose a cap on funds for the larger facilities are apparently convinced that most, if not all, developmentally handicapped persons will have their lives improved by "normalizing" their environment by placing them in "least restrictive" facilities in urban neighborhoods. We who are parents of severely handicapped children know this is a fallacy. As parents of clients served by both the institutional and community-based facilities of Presbyterian Ministries, we know that such thinking results from a lack of understanding due to the lack of experience with the care, training and custody of these persons. For the less severely handicapped individual with few behavioral problems who can be trained to function in a society with considerable independence, there is no doubt that a small community-based facility is appropriate. In the case of Evergreen, such persons are placed in such facilities. However, those who are in the intermediate care facility are there because their disabilities require that they be in the larger facility. These persons range from those who are profoundly retarded and require close care and supervision to those who have a fair degree of mental acuity but are functionally retarded because of related brain and central nervous system disabilities and are unable to function outside of a sheltered environment because of extreme social immaturity and other behavioral problems. Many families have been through a disheartening search for an ideal haven for a son or daughter incapable of living outside of a sheltered environment who cannot be kept at home without a complete disruption of family relations. Many have tried the small commmunity based facilities and have found them entirely unsuitable for the care and training of their children. We have felt our prayers answered by finding an institution willing to accept and to appropriately train and care for our children. It is a great comfort that they reside in a rural area with park-like grounds with clients living in small unlocked units and cared for by a trained staff able to provide 24-hour a day supervision.

The nightmare raised by this bill is that these adult clients will be removed abitrarily from this facility by lack of funding or bureaucratic fiat and placed in an environment with which they could not cope. We would fear for their health, their safety, their access to drugs and alcohol and the hundreds of other tragedies that experience has taught us would likely befall them without institutional care and supervision. We also know from bitter experience that the members of society they would encounter in neighborhood settings would not be sympathetic to them. Many of the disabled cannot interact with the community and the community will not accept them, particularly those with bizarre or inappropriate behavior. In most cases they need to be protected and insulated from society, not thrown into it as innocent victims of their handicaps. To abitrarily assume that it is the inherent right of every mentally handicapped person to be thrust into society despite his inability to function effectively, defies common sense. So far as we are aware, there are no available statistics to guide us in identifying those who should be in larger institutions and those who should be in smaller community facilities. Since each individual's case is unique, there can be no way of making such separation without an objective evaluation in each case. For this reason it seems obviously unwise to impose any restriction of funding based on size of facilities. Surely the encouragement of the use of the smaller community-based facilities can be accomplished without limiting the funds available for the care of those in the larger facilities. The handicapped placed in each type of facility will then be based upon the evident needs of each individual and not on an arbitrary and discriminatory funding limitation.

Another important reason for our appreciation of the services now afforded our adult relatives is continuity of service. For parents of advanced age, it is most comforting to know that their children who will require lifetime care can have that care in a state or privately operated intermediate care facility that can reasonably be expected to have a continuing existence. The small neighborhood facilities sponsored by this legislation will, in many cases, be operated by private individuals for profit. It is not reasonable to expect that, despite the best efforts at regulation and inspection, there will not be a wide variation in quality of care, frequent closings and changes in personnel and locations. These facilities will be entirely unsuitable for those needing lifetime care and custody in a sheltered environment.

In view of the foregoing, we urge that the bill be amended by striking all of the provisions of Section 4.

The proponents of this bill state that some of the larger institutions have not provided quality care, which has resulted in litigation and unfavorable publicity. We are pleased that this is not the situation of Evergreen Developmental Center. However, to the extent that the intermediate care facilities now receiving federal funding are not providing quality services, it is hoped that additional oversight can be provided in this bill in order to correct the situation. We strongly urge that any deficiencies in the present institutional facilities not be used as a reason to restrict the only facilities capable of caring for a large segment of our handicapped population. As Senator Dodd correctly observes in his remarks in the Congressional Record on reducing funds for the larger facilities, "it is important that we avoid throwing the baby out with the bath water" and "I hope that the bill will be amended to improve quality assurance at the institutions as well so that retarded people will receive quality services, regardless of their place of residence."

Finally, we note that this bill defines the class of handicapped individuals eligible for community and family support services as those with a "severe disability" corresponding with those eligible for Supplemental Security Income benefits under Section 1614(a)(3) of the Social Security Act. This definition appears to be broader and more definite than Section 1905(d) of the Act which defines those eligible for admission to intermediate care facilities as "the mentally retarded or persons with related conditions." Since there is no generally accepted definition of mental retardation and severe disabilities are best identified by the more comprehensive definition of those meeting the test for SSI benefits, it appears that this difference is likely to result in discrimination against some severely handicapped individuals needing the services of intermediate care facilities. We therefore suggest that Section 1905(d) of the Act be amended to make clear that eligibility for title XIX Medicaid funding is available to the same class of handicapped individuals for admission to intermediate care facilities as for those entitled to receive family support and community home services as provided in Section 1905(r) of the new bill.

Friends of North Mississippi Retardation Center
P. O. Box 967
Oxford, Mississippi 38655

April 11, 1988

Re: Senate Bill 1673/House Bill 3454

Dear Ms. Wilcox and Mr. Mihalski:

As parents of a profoundly retarded daughter, it is with great concern that we write you about Senate Bill 1673/House Bill 3454. It is our understanding that Senator John H. Chafee is again introducing a form of the Community and Family Living bills previously introduced. Although much talk is being generated that this new legislation is one of open-mindedness and compromise, the underlying issues in the law appear to be the same. Essentially, federal dollars will be withheld from the over-fifteen bed residential facilities and put into a community system for all mentally retarded persons, regardless of severity of their retardation.

Our daughter is presently a resident of North Mississippi Retardation Center in Oxford, Mississippi. She is twenty-one years of age and has been a resident since 1977.

As you can tell, we did not institutionalize her until she was ten years old. We had placed her in every public education facility that was available to help meet her needs at that time and finally had no other alternative but to place her at NMRC. Each year NMRC re-evaluates her condition and makes a recommendation to us as to the best possible facility available to meet her needs.

It is unfortunate that Senator Chafee does not appear to be aware of the necessity for continuity of services for the mentally handicapped. As parents, we should have the right to choose the kind of service that will benefit our child. All previous federal regulations have mandated that mentally handicapped residents be served in the least restrictive environment and be afforded programs or services that are set out for that particular individual and their specific needs. This Chafee legislation certainly DOES NOT take individual differences into account.

We would give anything to have our child in a facility where she could be helped during the day and come home to us at night, but because of her condition, it would almost be impossible for us to maintain a "normal" enviroment for our two other children who do not have any disabilities.

Many mentally retarded persons are able to lead productive lives in the community, although this transition is much smoother with support and assistance from staff. If each individual person is to receive the kind or programming and services tailored to their special needs, then these community programs would need to become "mini" institutions for many of the severely handicapped. Physical Therapy, Occupational Therapy, Speech/Language services, as well as many other services, including Social Services, are necessary links between family and individual, and additional training for areas of self-help and daily skills are all necessary in order to meet individual needs. Most of the time, the institutions are able to recruit professionals to meet the demands of these severely handicapped persons. Since our daughter is profoundly retarded, the one area that she can be helped in is with her self-help skills and language development; therefore, she would be one of the children that would benefit greatly from this "special" help. It would be extremely difficult and costly to provide these kinds of services within community settings.

We personally cannot understand the underlying motive and NEED to phase out state institutions. We understand the need for expanding community services, but not at the expense of institutions that can best serve the severely mentally handicapped. One of the best exercise programs that our daughter participates in is the acuatics programs at NMRC. She benefits greatly from this exercise. Also, there are many extracurricular activities that she is involved with and because she has to have total supervision, it would be hard for her to continue such a program in a less controlled environment.

We hope that you will consider the "depth" of this Bill and even though it does have some good aspects, the underlying thrust of this Bill is it would limit Medicaid funding to institutions which would ultimately make the institutions have to cut back on services and programs which could eventually close some cottages on the campuses, as well as completely closing some of the retardation centers.

Thank you for your time and we pray that you will consider this Bill seriously and will vote against it's passage. There are many excellent institutions in this country as well as many excellent group homes in this country. I trust that you will not support one at the expense of the other.

Sincerely,

Reed & Sondra Davis

Reed and Sondra Davis
1112 Grant Circle
Oxford, MS 38655

Frontenac Venture
Company

208 South LaSalle Street Room 1900 Chicago, Illinois 60604 Telephone 312 368-0044

April 5, 1988

Ms. Laura Wilcox
Hearing Administrator
Committee on Finance
Dirksen Senate Office Building, SD-205
Washington, DC 20510

Dear Ms. Wilcox:

Though S.1673 or H.R. 3454 helps with the removal of institutional bias and would make funding from medical dollars available to community-based support services, this bill in its present form could be DEVASTATING to people with mental retardation and the tax-paying citizens of the U.S. Thus I urge you to NOT SUPPORT the Chafee/Florio Bill S. 1673/H.R. 3454 in its present language. To be acceptable, the bill needs to: 1) guarantee funds with increases equal to inflation to all providers of services in the private as well as public sectors, regardless of size; 2) guarantee a variety of living and working options from which the individual, his/her parents or guardian can choose; 3) guarantee affirmative action for sales of existing property at a cost not less than the development of alternative living environments; 4) guarantee affirmative action for staff and staff re-training; 5) guarantee appropriate placement and training for displaced individuals; 6) allow for contiguously located living arrangements; 7) allow for an array of living environments (both smaller and larger); and 8) guarantee the right of each individual, his/her parent or guardian to choose their living environment.

Please do not allow S. 1673/H.R. 3454 to become law without addressing the above concerns and guaranteeing the right of choice and funding to people with disabilities.

Size of facilities, the ability to have contiguously located properties, quality of services, and economics are crucial areas of concern for our nation's disabled individuals and tax paying citizens in S.1673/H.R. 3454. BIG is not automatically bad and SMALL isn't always better!

Please keep me informed on the decision of your committee regarding S.1673/H.R. 3454. Thank you for your efforts and consideration of the above request.

Sincerely,

Martin J. Koldyke

MJK/chg

March 17, 1988

Senate Finance Subcommittee on Health
To: U S. Senators Chafee, Mitchell, Weicker, Chiles, and Graham

Re: Senate Bill 1673 - Hearing Scheduled for 3-22-88 at 9:30 A.M. in Washington, D.C.

It would be a tragedy for this bill to pass as is because it does not address the needs of the 1.5% of the mentally retarded population, i.e., the profoundly medically involved/mentally retarded children whose survival depends on high tech quality INSTITUTIONAL care. This does not refer to the rhetorical snake-pit metaphor but to the first rate medically-oriented residential facility required to properly care for these children. They and their families have been devestated quite enough. Please make this bill more comprehensive by continued proper funding of quality ICFMR's. In a country that accommodates the Federal procurement of $400.00 coffee pots and $600.00 toilet seats, surely a few dollars can be found to properly care for these critically unfortunate children.

Sincerely,

Mr. and Mrs. David D. Gilman

20 Compass Island
Fort Lauderdale, Florida 33308

NOTE: Our letter is intended submission and inclusion in the printed record of the hearing on March 22, 1988.

GREEN LINE PARENT GROUP, INC.

MENTAL RETARDATION CENTER
CAMARILLO STATE HOSPITAL
DIVISION 4 BOX A
CAMARILLO, CALIFORNIA 93010

Dear Senator Bentsen:

Relative to the Medicaid Home and Community Quality Services Act of 1987 (S. 1673 and H.R. 3454), we have carefully analyzed the bills and listened to lengthy presentations on them by two of the bills' principal sponsors and proponents, the Association for Retarded Citizens and the United Cerebral Palsy Association. On that basis we are willing to concede that there may be problems in Medicaid rules that adversely affects the constituencies these organizations represent, but we strongly oppose the bills because we are convinced they will create more problems than they solve, particularly in the following two areas:

First, Section Four of the bills would restrict Medicaid funding to all over-15-bed residential facilities for the developmentally disabled. The manner of accomplishing this "cap" on such funding is to freeze it at its current level and only to allow its increase if the cost-of-living index exceeds six per-cent. The immediate affect in enactment of this section would be to demoralize all the providers of over-15-bed facilities by signaling their eventual but inevitable demise. This could only have an adverse affect on the residents of those facilities. The staff, upon whom their very lives often depend, would soon leave for more secure jobs. This would be a very destructive loss. These employees are hard to replace under the best of circumstances. The final result would likely be the loss of what many believe is an essential element of the care system. The one, in fact, that now provides the most reliable and highest quality care to about one hundred thousand developmentally disabled people nationwide. In California, for example, the only facilities accredited in accordance with the high standards which the bills' proponents endorse, those of the Joint Commission on Accreditation of Facilities for the Developmentally Disabled, are the seven state operated Developmental Centers dispersed throughout this region and providing the highest quality care to more than 7,000 people.

Implicit in the bills is the theory that there is some inherent benefit in under-16-bed facilities. To say the least, this is a controversial, argumentative, and unproven belief.

Second, the eligibility aspects of the bills also deeply concerns us. There seems to be no question in anybody's mind except the bills' proponents that under the bills' expanded definition of eligibility and liberalized access to Medicaid funding that the service population will increase immensely, probably four-fold, according to California Health and Welfare Agency officials. And with statutory spending limits in this and other states restricting participation in such funding, passage of these bills in their present form could have a devestatingly adverse affect on the over one hundred thousand developmentally disabled residents of over-15-bed facilities nationwide. Envision four times as many straws suddenly poked into the same old Medicaid milk bottle.

Our parent group has a long history of actively supporting good quality community care facilities. But we support them as a continuum of care to include both large and small facilities. We believe, along with many impartial authorities, that only in such a system is the best opportunity provided for achieving the true least restrictive environment suitable and appropriate for the widely divergent needs of developmentally disabled people.

We oppose the Medicaid Home and Community Quality Services Act because it is contrary to the above well-founded principle. It is also prejudicial in its under-16-bed bias, unneccessarily demanding on current resources, and based on controversial and unproven ideology.

Very truly yours,

Rose Zachowski

ROSE ZACHOWSKI
President

j

OBJECTIONS TO MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT OF 1987)S.1673).

1. In its present form, the bill would spell the eventual end of facilities with more than 15 beds now providing complete training, medical and other services on a 24-hour basis to persons with mental retardation. This because the bill would cap Medicaid dollars for institutions at current levels, except to the extent that the cost of living exceeds 6%. The result would be that funding for these facilities would be reduced to about half of today's value within 15 years. That would make it very difficult, if not impossible to continue quality care for residents of institutions.
   It is clear that additional funds should be made available for community homes and home care. But they should not be provided at the expense of established, fully staffed institutions specially geared to the needs and care of the mentally retarded.

2. That some residents of large facilities would be better served in properly operated and supervised community homes is not questioned. But since 1971 populations of state institutions have decreased by 47 percent, and most of the remaining residents are severely and profoundly retarded. Many of these have mental ages of only a few months, are non-verbal and non-ambulatory and have multiple disabilities, including blindness. A serious flaw in the bill is that it tends to stereotype persons with mental retardation, wrongly assuming that all such persons can be mainstreamed, regardless of the degree of retardation. This pollyanna notion is utterly devoid of reality.

3. The bill does not provide for proper participation by families in decisions about their children's future. It appears to leave their inclusion or exclusion up to bureaucrats serving on decisionmaking panels. Parents should be fully involved as a matter of course. (They know what's best for their child- children).

4. Proponents have claimed there is now a consensus on this bill. This is not true. The bill is highly controversial. Over a hundred parents and other organizations are strongly opposed, including many church groups.

5. Many parents are concerned over the stability of community programs. Article in Mental Retardation (Volume 23, No.3) published in June, 1985 by the American Association on Mental Deficiency reported on a study made on the stability of residential facilities. This study, supported by a grant from the Health Care Financing Administration of Health and Human Services, found that only 62.3% of facilities serving one to six residents in 1977 were still in existance five years later. During the same five year period 70.1% of facilities serving 7-9 residents in 1977were operational in 1982. Survival rates increased as size of residences grew larger with 99.3% of facilities with 500 plus residents remaining. This is not very encouraging. The Public Interest Law Center of Pennsylvania (that conducted the suit that resulted in the Deinstitutionalization order for Pennhurst, a facility for the mentally retarded) has filed a suit, on behalf of the Association

for Retarded Citizens of Pennsylvania because of abuse and mistreatment of Pennhurst residents now living in group homes in Philadelphia County. In the motion, signed by Frank J. Lasky, was included the following information:

> The special management unit of the state that does the monitoring of group homes, was to have monitored 500 homes in Philadelphia in a two year period. In that period they monitored only 200 of the 500 homes. Deficiencies were found in these homes, and reported, but no action had been taken.
>
> Of the 200 homes monitored, the following information was filed in the motion:
>
> 57% had out-of-date programs.
> 83% lacked services.
> 45% had no programs for taking residents out in the community.
> 68 of the homes did not provide adequate therapy.
> 38% had rapid staff turnover.
> 31% did not have adequate staffing.
> 27% had medical errors in the administration of medication to the residents.

Relocation of persons with severe and profound mental retardation would often be both illogical and inhumane. Effect on the individual would be traumatic and doubly so should he be transferred a second or third time because of dissolution of or rejection by a small community unit.

6. The "grand and noble" experiment of the early sixties which moved people from mental institutions to their communities with disastrous results should give pause for thought to those pressing today for mainstreaming all persons with mental retardation now residing in facilities - both public and private - with more than 15 residents. Many of the mental patients sacrificed to the whims of theorists pushing this program are among today's street people.

7. The bill would largely eliminate discretion within present programs which allows states to define client eligibility and the types of services to be delivered within the context of their own programs, policies and service system needs.

8. The misguidednotion that small (with regard to residential facilities) is always better seems to underlie philosophy of the proposed legislation.

9. The bill ignores requirement for freedom of choice as contained in the Social Security Act. It ignores the need for varying levels of services reflective of a resident's condition. It would lead to litigation from disabled persons, their families and guardians who are currently satisfied with the quality of services received in both public and private facilities.

10. State operated facilities would not be the only ones adversely affected by the bill. Many private schools which rely heavily on donations to cover both operating and construction costs would also be negatively impacted. The bills would tend to eliminate this important revenue source. Contributors would hesitate giving to a facility whose future is limited. The threat of liquidation would also adversely affect morale of the staffs of large facilities. Many dedicated persons would be impelled to leave their chosen careers.

11. As acknowledged by Senator Chafee himself, reaction to S.1673 and the two earlier versions has been overwhelmingly against them.

12. Large facilities must satisfy high standards set by state and federal agencies which are constantly monitoring them.

13. In their emphasis on need for "community living" proponents of the bill overlook the fact that most large facilities are in themselves communities complete with chapels,gyms, swimming pools, recreational equipment, canteens, attendance at local sports events and other features making for a community setting.

14. The bill would include as "individuals with a severe disability" literally thousands of persons who are currently receiving SSI benefits, and who therefore would be eligible for the expanded "medical assistance" under Title 19. as a result of injury, or other disabling conditions. This naturaly will substantially increase costs.

15. The bill would virtually close the door to those persons with severe disabilities who in no wise could function in the community. Admission to large facilities which only can satisfy their needs would be made most difficult. Any program for the severely retarded should be tailored to the individuals needs. No one should be shunted to a community home who can be better cared for in a stable,fully equipped and staffed facility. Again, we refer here to persons whose degree of disability is so severe that mainstreaming, however well intentioned , would be a serious mistake.

16. Our concern about the bill does not mean we do not recognize the need for expanding community and home services. What does worry us is the bill's distinctly anti-institution bias. It would be tragic indeed to dismantle what has taken years to build and perfect. Why must transfers from large to small settings be practically mandatory? We only wish that a key premise of the bill - that all persons with mental retardation, regardless of the degree can in effect be normalized - were true. We we know better, from sad, heart-breaking experience (and who.but a parent should know what's best for a child?). We have run the complete course: we've had our children in our own homes, we've participated in myriad programs involving the mentally retarded, some of us have tried small, expensive schools. None of this has has worked and in a state of near-desperation many of us placed oor children in institutions. Happily, this has proven to be the best thing that could have happened for our children . They are happy and so are we.

17. The bill provides that states will set standards and monitor services offered in small community settings whereas institutions will be monitored under federal "look behind" procedures. We question why there should be separate procedures relative to community facilities in 50 states.

18. Implementation of this complex bill would prove to ge an administrative nightmare.

Mailing address:
6134 Orleans Ave.,
New Orleans, La. 70124

Terrence R. Turner
Parent's Association
Hammond State School
hammond, Louisiana

1018 10th Street
Silvis, Illinois 61282
March 29, 1988

Ms. Laura Wilcox, Hearing Administrator
Committee on Finance
Dirksen Senate Office Building, SD-205
Washington, D. C. 20510

Dear Ms. Wilcox and Members of the Committee,

At the invitation of Chairman Mitchell, I submit the following observations for possible inclusion in the printed record of the hearing of the Senate Finance Committee's Subcommittee on Health held on March 22, 1988 regarding S. 1673, the Medicaid Home and Community Quality Services Act of 1987.

In thirty-five years of teaching mentally handicapped students in Illinois schools, I have seen many families strained to the breaking point by the financial burden of providing services to their handicapped family members at home. Some few wealthy families survived intact. Others gave up and gave up their loved ones to institutional care. Still others became insolvent, the remnants of their once productive family receiving welfare, and the client still receiving marginal services at best.

Now, through S. 1673,The People of the United States, through their Congress, have a real opportunity to secure the Rights of Life, Liberty and the Pursuit of Happiness to a long-neglected segment of Americans. At a mere fraction of the cost of institutional care, S. 1673 plans to deliver quality support services to handicapped persons in their own family homes and community-based facillities.

This subcommittee is charged with the task of developing the most effective and efficient means of financing the deliery and accountability for these services, with the least chance for escalation of administrative costs. Medicare already has machinery in place and as good a track record as any other services-funding bureau or agency. May I suggest a categorical services-delivered per client voucher system submitted to the states for payment into Medicaid funds from their savings in institutional care.

Paralell action by the Congress to reduce health care costs for all Americans -- including Medicaid recipients is now a high priority issue with most of us "back home" constituents, and will gain importance with passage of this Bill.

Thank you for this opportunity. I hope these observations prove helpful.

Cordially yours,

Mar Carty Hanson

6175 Old Baton Rouge Hwy.
Hammond, Louisiana 70401
April 15, 1988

Ms. Laura Wilcox
Committee on Finance
United States Senate
205 Dirksen Building
Washington, D.C. 20510

Dear Ms. Wilcox:

I am writing to voice my concerns regarding and opposition to The Chafee Bill (S1673). Being the father of a daughter who is now residing at Hammond State School, a facility for the mentally retarded, it bothers me greatly to think of the impact this Bill would make if it should become a law.

My daughter is totally dependent upon others to provide for her needs. She is non-ambulatory and spends all of her time either in a bed or in her wheelchair. She is non-verbal and has a tracheostomy and gastrostomy. Because of her disabilities, she requires constant medical supervision.

At Hammond State School she is involved in hours of training appropriate for her condition. Her daily schedule includes therapy sessions and emphasis is placed on environmental awareness and socialization. I would never want my daughter to lie in bed secluded from others with lack of contact.

I know of no better placement for my daughter. She requires the services available at a large institution where she does not have to be transported in and out of vehicles to reach those services.

My wife and I are in ill health and cannot keep our daughter at home. There are no family members able to provide the care she needs in their homes either. Without facilities such as Hammond State School I could not rest from worrying about my daughter.

Please - let's not allow the Bill to become law. We need large facilities for the severely and profoundly retarded.

Sincerely Yours,

Mr. Marion Thompson

Statement of Marylanders for Community and Family Living
to Senate Finance Subcommittee on Health
on S.1673 - Medicaid Home and Community Quality Services Act

My name is Stanley S. Herr. I am Co-Chairperson of Marylanders for Community and Family Living (MCFL), a broad coalition of people from organizations responding to the needs of individuals with severe handicaps such as the Association for Retarded Citizens, the League for the Handicapped, the American Association on Mental Deficiency, the Education Center of Sheppard Pratt, the Law Clinic of the University of Maryland, the Epilepsy Association of Maryland, United Cerebral Palsy of Maryland and the Maryland State Planning Council on Developmental Disabilities, as well as a number of parent advocates of sons and daughters with disabilities.

In Maryland, services for persons with a wide variety of developmental disabilities (other than exclusively mental illness) are provided by the Developmental Disabilities Administration (DDA) of the Department of Health and Mental Hygiene. In an official study made for DDA by the University of Maryland, it was shown that 5523 persons were waiting for services from that state agency as of July 1, 1987. Two comments should be made with respect to that figure: 1) It represents only those who are on official waiting lists maintained by service providers around the State by virtue of having identified themselves to these providers. As advocates we know, and the professionals will confirm, that there are countless others who have a need for services but have not made themselves known because of reasons of pride, ignorance, or their awareness that such services would not be made available within a reasonable period of time even if they made application for them. About 25% of their caregivers are believed to be over 65. 2) The current waiting list figure has remained essentially static for a number of years in spite of the best sustained efforts of advocates to convince the State to commit additional resources to its reduction. Moreover, the severity of the waiting list problem continues in spite of the fact that of the 5523 people officially listed, 54% indicated that they were in urgent need of day services and 36% in urgent need of residential services.

Why is this problem so intractable?

Primarily because of insufficient funding for family and community type services and facilities. This, of course, is acknowledged by the state administrative agency charged with dealing with the problem. In its official handout to persons considering making application for service, the state DDA is careful to point out that "the length of time before you receive services from DDA depends on the amount of money that the DDA has to spend on services. . . . While the DDA tries to serve as many people as it can, there are many more people asking for services than there is money to buy the services being requested." The state through its executive budget system, has been unwilling and would contend that it is unable to allocate, over the years, sufficient funds to serve all those on the long-standing waiting lists. One reasons for this funding shortfall is that Maryland like most other states, has had a policy of moving people who are inappropriately placed in large institutions for the mentally retarded or mentally ill to community facilities. Unfortunately, however, the per capita costs of maintaining each such person in the institution has not been shifted in a like amount to finance family or community living alternatives for each person transferred to a community setting.

What can be done about the problem?

If it is true, or we believe it to be, that increased community and family expenditures are the key to answering the waiting list problem, then anything which would encourage the states to enlarge those expenditures would have a direct beneficial impact. S.1673 provides the key for unlocking the door. Essentially it does so by limiting federal payments for services in large institutions. At the start of the first fiscal year after enactment, federal financial participation (FFP) for large SNF, ICF and ICF/MR facilities with 16 or more beds would be limited to the amount the state got for the individuals with severe disabilities under 65 years of age in the previous fiscal year. That freeze would be permanent except to the extent that inflation might exceed funds which it would thereby "save" by this limitation on its expenditure for institutional care to expand community facilities and family care assistance. Doing so would assist those states to fulfill the goal expressed in their statutes and regulations (as in Maryland) to provide needed and appropriate community facilities and services for all of its severely developmentally disabled citizens. Encouragement for the States to so act is provided in other provisions of S.1673. For example, any costs in administering the provision of community and family support services would be treated in reimbursable administrative costs under the state's Medicaid plan; the state would be required to expend from non-federal funds at least the amount it expended during the base year for community family support services adjusted for inflation; and the state would be required to provide an implementation strategy to fulfill the aims of its Medicaid Plan in which it would set forth the specific objectives and a five-year schedule to expend and improve community and family support services for eligible individuals with severe disabilities, including those found to be residing in inappropriate large facilities. At the same time, the state would maintain such of those larger facilities it considers necessary to accommodate the declining number of individuals whose evaluation indicates that that is the most desirable setting for them and that is available for them in the array of services to meet the requirements of their individual written habilitation plans.

This statement concentrates on the funding provision of S.1673 as the technique best designed to encourage the placement of the largest number of severely disabled individuals in community settings and to help families maintain their disabled members within their existing home environments. There are many other provisions of the bill which would tend to improve the quality of those community and family support services and to assure their continuity. Those provisions would help to move the covered population toward greater independence and add to their ability to better participate in all aspects of community life and social, economic and recreational activities. In the intent of brevity, this statement does not discuss those provisions in detail, but their omission should not be construed as indicating any lack of importance. They will be covered by the comments of other witnesses before the subcommittee.

Concerned Families of Hazelwood Hospital

Members of the United States Senate and House. My name is Louise G. Underwood and I represent over 1000 caring and Concerned Families of Mentally Retarded from the state of Kentucky.

Concerned Families is a member of Voice of the Retarded (VOR) -Parents Network and many more National Groups of families and friends of children who reside in ICF.MR. Facilities through-out this great land.

Concerned Families is a non-profit organization of families and friends dedicated to protect the rights of the residents of Hazelwood ICF.MR. in southern Jefferson County. Louisville, Kentucky.,and the mentally retarded through-out the United States , and to guarantee continued quality care , and to preserve and improve ICF.MR. Institutions providing a quality life for those individuals who are unable to care for themselves.

If I may , I'd like to give you the results of our experiences with institutional care and community care in Kentucky over the past 15 years.

As one of the leading states in developing community services for a mentally retarded in the early 1970's Kentucky started a program called the "Circle of Care". The purpose of the program was to place MR children back into communities under the supervision of Regional Comprehensive Care Centers. At face value the program appeared to be a good one but after operating about three years it was abandoned. Poor monitoring, excessive cost, and self interest resulted in inadequate care, neglect and even death for some of our helpless MR children. Some are alive today because they were fortunate enough to be returned to the safety of our state residential facilities.

We believe that community services should be developed for those that need to be in the community but not for all . We advocate for community services but NOT at the cost of our institutions. The Chafee Bill would eventually close our institutions by reducing services. We have experienced these things many times in the past.

In 1975, Kentucky began another well-meaning deinstitutionalization effort called the "New Directions Program". Again, millions and millions of dollars were poured into another program designed to care for the mentally retarded in the community. This time the state's child welfare departments social workers were plugged into the system to assist the comprehensive care centers social workers with many other professional organizations in monitoring placements after the children left the state institutions. The program looked great on paper! Part of the program involved placing profoundly retarded, nonambulatory children into the very best community skilled nursing facilities. However, before long problems began to develop. Monitoring by inexperienced social workers, conflict between agencies, improper or inadequate placements and increasing cost all began to lead to neglect and rapid movement from one type of placement to another. Children became lost in the system. Our Hazelwood children who were placed into very fine community, skilled nursing facilities started to deteriorate and some began to die. One of our friends at the facility did a study and found that the life expectancy of a profoundly retarded, non-ambulatory person with no self help skills and who had chronic medical problems had a life expectancy of 8.8 months after leaving Hazelwood. A similar type of child at the facility but one who was too weak to be placed into the community, had a life span of 2.3 YEARS at Hazelwood. I want to emphasize that only the healthiest and strongest left Hazelwood for community placement. Once they were in the community, their life spans were dramatically shortened. In April 1978, Roger T. (an 18 year old young man) was placed out of Hazelwood into a very good community skilled nursing facility which specialized in caring for such persons. Five days after leaving Hazelwood, he died. Roger's death and the deaths of others resulted in a suit against the state of Kentucky. Because the state agreed to halt such community placements the suit was dropped. This time it had taken the lives of some of our mentally retarded children to inform the professionals what we as parents and relatives had already known. That is---- If our children could have been adequately cared for in the community, we would have kept them at home with us in the first place!!

In 1979 Kentucky began a third deinstitutionalization effort and called it the "New Neighbors Program". Again, the state had the non-profit, comprehensive care centers playing a major role in the program. This time, however, the state's own Child Welfare social workers were not included in the after placement monitoring process. In previous deinstitutionalization efforts these state social workers had made the comprehensive care centers too uncomfortable by reporting too many problems. I should like to remind you that these community comprehensive care centers are now functionin at less than 70% capacity then when they were back in the days of plenty. Some in Kentucky have taken bankruptcies and others are fighting for their financial survival. Staff have been reduced, personnel turnovers are frequent and funding sources are becomming increasingly uncertain. In spite of all this instability, Kentucky's Division for Community Services again contracted with the Comprehensive Care Agencies and continues to use them to develop placement sites and then to do their own monitoring. It is quite believable that the Comprehensive Care Centers are not going to find fault with a program from which they financially benefit and it is conceivable that the state's Division may hesitate to criticize its own program if things don't go well. Again, the welfare of our children is exposed! This time the state social workers are not in the field to monitor what is happening to our children. Twice before, deinstitutionalization programs could not function even in times of better funding, more personnel and more resources so it is no wonder that we have again began to hear of abuse and neglect. Recently we were able to obtain a few sample reports concerning some of the ~~children~~ placed into community placements from state residential institutions under the New Neighbors Program. I have attached copies of these reports to materials I gave to the committee. These reports show that many of the community placements are anything but successful when you compare the care these MR persons received in our state residential institutions.

We parents and relatives of the mentally retarded in state and private institutions number over 1000 families in Kentucky. We have had extensive experiences with community placements. We know that community placements are not appropriate for all types of mentally retarded children. We know that there is a significant difference between the following:

1) A profoundly retarded child.
2) A profoundly retarded child who is non-ambulatory and who has minimal self-help skills.
3) A profoundly retarded child who is non-ambulatory and who has minimal or no self-help skills and who is further effected by chronic medical problems. Children to whom a common cold becomes life threatening pneumonia because their Immunological defense systems function poorly.

Many authors of community MR programs deal with the later two catagories of MR children by omission. As an example, I am including to the committee a copy of one such program designer's definitions of various classifications of Mental Retardation. In it he completely ignores the existance of the very type of child that fills our Hazelwood ICF.MR. facility. Such children as these make up approximately 10-15 % of all mentally retarded children. Such children would die without intensive, ongoing and well-monitored care as is found in Kentucky's state residential institutions.

This type of mentally retarded child cannot be successfully placed into community settings unless tax payers are ready to spend thousands of dollars . In 1983 (See attachment) of what is cost to just start placement for one of our Hazelwood higher functioning residents. It cost in 1983 about $ 26.000.00 to serve this resident at Hazelwood. The cost in 1983 was computed by Kentucky's Division for Community Services who were very eager to place children out of our fine state institutions. Knowing them as I do, I would say the figures would fall short of the true cost of community care for this person. This person has since been placed into the community and it is very appropiate for him. If this young man receives the same types of services he had available to him at Hazelwood the cost could be $ 100.000.00 per year. At Hazelwood currently it would cost about $ 40.000.00 per year. But I do not believe he can get all these services in the community. I do not believe he will be able to have therapy, medical care and teaching staff available to him when he needs it.

We believe that if a M.R. residents needs to be in the community those services should be available to him . But don't tell us the families that it is cheaper to serve an M.R. like our children at Hazelwood in the community because we have experienced every service under the sun in the community.

Hazelwood children are Medically fragile, deformities, bed-ridden- cannot walk, talk, or let any of their needs be known.

Senator Chafee S.B. # 1673 and Floria's H.R. 3454 will mean that by putting a "Cap " on Medicaid funds for our Institutions that services will be reduced and many of our children will die and all of.our ICF.MR. Institutions will be forced to close. We know and have lived through all the horror's of seeing our children carried off to nursing homes and community placements where we know for a fact that they cannot get anywhere near the services they got in our ICF. MR. facilities.

You cannot get services for our types of children in the community. How many of you know doctors, psychologist or physical therapists who make house calls? In some areas of Kentucky there is not a doctor for 50 miles and not a physical therapist for 70 or more. The Hazelwood children of whom I speak need more. They not only require ongoing preventive medical care but medical treatment that must be rapidly available if it is to be effective.

Another type of mentally retarded person poorly suited for community placement is one who has severe behavioral problems. Some mild behavior problems may be successful but I am concerned about the more severe situations. I am giving the committee copies of sample reports I obtained which show what has happened to such mentally retarded persons and to the individuals who cared for them. Imagine the actual cost of taking care of a MR person with severe behavioral problems in the community whereby sometimes one-to-one care around the clock is not sufficient.

MY POINTS OF CONCERN ARE THESE:

1- Community care is NOT less expensive than institutional care for some children. Indeed, it is far more costly than institutional care.

2- Institutional care can provide more services at a lesser cost for many children because all services are located in the same facility. This is especially true for MR children who require a higher level of care.

3- There are insufficient numbers of doctors & therapists available in all communities, to travel from home to home in order to provide good care. Even if there were, the cost would be out of sight.

4. Community care programs for the mentally retarded handled through the Comprehensive Care Centers have not been as successful as the various Associations for Retarded Citizens' Public Relations men would have you believe. Kentucky has gone through three such efforts and spent millions of dollars with little to show in proportion to the amount it used.

5. Effective Community care programs for the Mentally Retarded must be operated directly by state agencies who are directly responsible for them. Contracting out for services, even with the best monitoring system, still adds excessive layers of administrative cost. An example: The state division for community services in Kentucky contracts with the Seven Counties Comprehensive Care Centers for community services. The comprehensive care center subcontracts with the Council for Retarded Citizens for these services. The Council then subcontracts with Community Living, Inc. who finally gets the job done. Imagine how much money is wasted through all these layers of administrative contracting. There are simply too many fingers in the pie! Community care for the mentally retarded is becomming a very large and lucrative business. It provides a solution for various organizations who are eager to maintain their financial security and expand their areas

of influence------and this is not always in the best interest of the mentally retarded child.

6. It is no more correct to say that one form of care is right for all types of mentally retarded children that it is to say only one form of medication is correct for all forms of illness.

7. This is but another effort, on the part of professionals who favor deinstitutionalization, to try to close our fine state and private institutions. We have dealt with these Associations for the Retarded for years and although their strategies change their ultimate goal remains the same. At home I have a newspaper clipping from several years ago that quotes one of the Association's officials. It boldly states:

   > "in our plans there is no room for institutions, large or small".

   I can assure you that this association does not speak for over 1000 families in Kentucky who want good institutional care for their children, such as we have in Kentucky.

8. If Senate Bill 1673 is approved, I can assure you the cost of care for the mentally retarded will greatly increase while the quality of care will shrink. The victims will be our children! The above also pertains to Bill H.R. 3454.

In closing, I should like to offer a few suggestions that might continue the same level of services and at the same time reduce the cost of such services:

A/ There are many MR persons who do not require ICF/MR level of care and who would do well in a lower level of care such as PERSONAL CARE with attached MR programming (PC/MR). Personal care is less expensive than Intermediate Care. Such a level of care could be offered both in institutions and in the community.

B/ Establish a level of care higher than the current ICF/MR level. Such a level could be called Skilled Nursing MR (SN/MR). This level would emphasize skilled nursing and medical care with programs to provide stimulation for the purpose of preventing regression. Heavy/intense training in self help skills would not be necessary here because many of these children function at less than a one year level. With permanently damaged nerves and muscles, the expectations of these children developing self help skills is remote, at best. Since intense programming and training accounts for 65 to 70% of the cost of operating an ICF/MR, a significant reduction in cost could be realized.

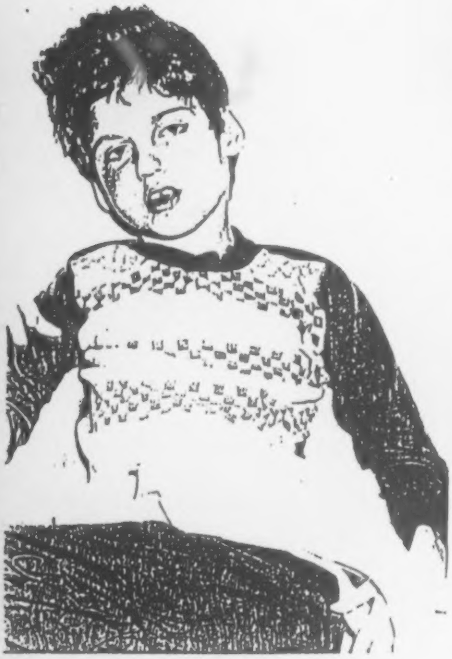
C/ Public law 94-142 is excellent for the handicapped and some higher functioning MR children. But for profoundly retarded children who are non-ambulatory, who have no ability to communicate, who have no self help skills, who are chronically ill and who, because of permanent brain damage, function at less than one year level and who will always be dependent--- I feel that busing such children as these to school across town on cold winter mornings is not normalization but speaks more of child abuse. Yet, we do this very thing to some 70 children at Hazelwood each day because the officials say we must do it to obey the law. Some of these children who require physical therapy inorder to stop contractures from developing, must wait to receive the therapy until their little tired bodies arrive back at Hazelwood, late in the day. The very programs these schools offer (as well as the various therapies which they do not) are all available at Hazelwood AT A FAR LESSER COST.

D/ Kentucky recently started providing an option for Medical Assistance to pay either for care in institutions or for care in the community. It is called Alternative Intermediate Services/Mental Retardation or AIS/MR for short. In other words, the state has just begun to financially support a system of care suited to the needs of the mentally retarded individual. Provided it does not become too costly, I believe this is the answer to the care that all of our mentally retarded children require.

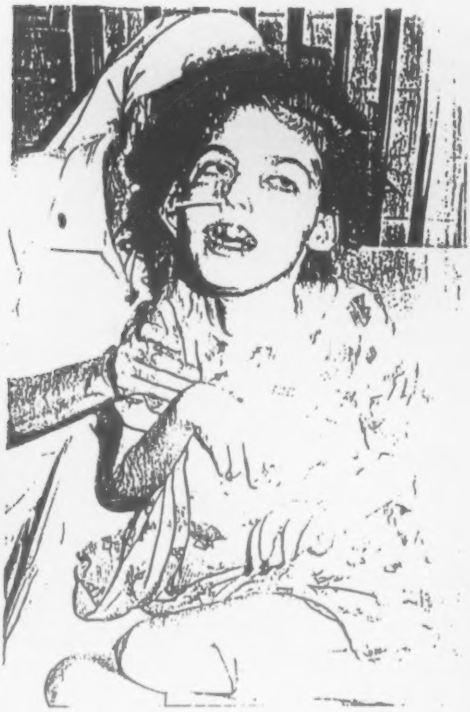
I thank you for your time in letting me express the feelings of our many Kentucky families. As you know, we are people who must work for a living and must take time from work to plead the needs of our children. Since we are not endowed like the various Associations, I can say as parents and relatives of the mentally retarded, that our concerns are sincere and without any motive other than good care for our very special children.

-Louise Underwood
President, Concerned Families
of Hazelwood Facility

Louise P. Underwood
Address: 3129 Bank St
Louisville, Ky; 40212



BEFORE LEAVING HAZELWOOD ICF/MR
FOR COMMUNITY PLACEMENT



AFTER RETURNING TO HAZELWOOD
FROM COMMUNITY PLACEMENT

OFFICE FOR PUBLIC ADVOCACY
State Office Building Annex, Frankfort, Kentucky 40601

Protection and Advocacy Division
564-2967

Defense Services
Investigative Branch
564-3765

Public Defender Divis
564-3754

July 25, 1983

Dr. Jeff Strully
Seven Counties Services (this is a community comprehensive care agency)
Box 628
Starks Building
Louisville, Kentucky 40202

Dear Dr. Strully:

I am a bit confused about the status of [redacted] application to the AIS/MR program. As I mentioned to you, I was told by Mr. Bill Draper that [redacted]'s estimated cost for community living has been placed at $40,000. I was later informed that a decision has, in fact, been made on [redacted] acceptance to this program. Please advise me if a decision has been made, if the cost estimate has been established, and if those seven residential slots are taken.

I understand that there may be some expensive initial costs in moving [redacted] into his own apartment. Early next week I will be receiving a report from Hazelwood ICF/MR as to what equipment belongs to [redacted] already and the purchase cost of any equipment [redacted] might need and does not own. I am also eager to work with Ms. Cassidy in identifying other resources in helping [redacted] establish himself in a new home in an inexpensive manner.

I would hope that before a final decision as to costs or acceptance is made from your agency that you would allow [redacted] time to obtain another cost estimate if deemed necessary, and to speak with you about the quality of the living situation [redacted] chooses to place himself in. I would assume that you would give his guardian and myself as his representative that same opportunity.

1983
Note: At Hazelwood ICF/MR this person's care cost $23,000 per year as opposed to $40,000 per year plus initial cost of moving & setting up the apartment plus medical needs.

NOTE: 1987

Now in the year of 1987 the cost for Hazelwood is approzimately $ 40.000 in the community today this would cost $ 100.000.00

I am sure that we can work together to ensure that the procedures taken to determine his eligibility are working towards [redacted]'s benefit.

Sincerely,

Pam Clay

Pam Clay, Residential Advocate
Protection and Advocacy Division

MARCH 14, 1978

82	Residents who have been placed out of Hazelwood from 6/1/71 to 3/14/78
-5	Returned to Hazelwood after placement (did not meet criteria, etc.)
77	Permanent transfers
-1	Residents not admitted to Hazelwood for treatment but only for "holdover" until they could be sent to TIP home.
76	Residents transferred
	15 died since transfer. Life span for those who died is 8.8 months (average). 20% mortality rate for placed residents.
376	Total admissions to Hazelwood
-12	Respite care cases admitted
364	
-76	Transferred from Hazelwood
288	Net Hazelwood admissions
38	Died at Hazelwood. Life span for those who died is 2 years (average)
	13 % mortality rate for Hazelwood Population

OF THOSE TRANSFERRED FROM HAZELWOOD:

Life span during stay at Hazelwood 2.31 years
Life span at transfer facility (nursing home) 8.8 months.

It should be noted that 14 transfers have been made within the past 8 weeks. Although these 14 have been considered in this report, such a recent concentration of placements (which is unusual) artificially decreases the mortality rate of placed residents. Prior to 8 weeks ago, placement mortality rate was 22.58%.

The 15 deaths (of residents transferred) are cases of which Hazelwood is aware. It is very probable that other deaths have occurred of which we are not aware. No surveys have been made during the past three months during which deaths of placed residents also may have occurred.

It should be noted that nearly all of the children who died at Hazelwood were very delicate children and were admitted in very poor condition. Examples: (at random)

Averbeck- very frail, prone to upper respiratory infections, chronically ill, totally helpless. Had to be turned, etc.

Douglas- Admitted as an emergency. Dehydrated, not eating, had bleeding ulcer. Very frail. Totally helpless.

Ravhill- Congenital heart disease, frequent cyanotic spells wherein could not breath. Frequent upper respiratory infections, Very frail and totally helpless, etc.

WHEREIN--those residents who were placed out of Hazelwood were in very good health with no serious or problem medical conditions. All they required was good basic day-to-day maintenance care.

ATTACHMENT TO THE PLACEMENT STUDY

EDITORIALS

TUESDAY, OCTOBER 27, 1987

The Courier-Journal
A GANNETT NEWSPAPER
Founded 1826

George N. Gill, president and publisher
David V. Hawpe, editor
Irene Nolan, managing editor
Stephen J. Ford and Ben Post, deputy managing editors
William L. Ellison Jr. and Mervin Aubespin, associate editors
Warren Buckler, Van A. Cavett, James Eddleman, Bert Emke, Carolyn Gatz and Laurel Shackelford, editorial writers
Hugh Haynie, cartoonist
Keith L. Runyon, editor of the Forum
Robert T. Barnard, associate editor of the Forum

Beyond the open door

THE MOVE to deinstitutionalize the mentally ill — to get them out of big "asylums" and out into the community — was widely acclaimed as an unqualified success in the 1960s and '70s.

Today we know better. Too little money was spent on community treatment programs that were supposed to replace institutional living. As a result, the mentally ill now constitute a large share of the homeless who wander the streets of America's cities.

Despite this, a group of well-meaning but misguided lawmakers in Washington is proposing the same approach for the mentally retarded and physically disabled. Led by Sen. John Chafee of Rhode Island, they are pushing legislation that would squeeze Medicaid funds that support the disabled in public and private institutions.

Much in this bill — the "Medicaid Home and Community Quality Services Act" — is desirable. It would provide federal funds for a wider range of services, including home care, and would help a larger number of the disabled. But to offset the added costs, the bill would freeze funding for institutions with more than eight or nine beds. Eventually, as the cost of living rose, the purchasing power of these funds would shrink, and the institutions would be forced to curtail services or close.

Even one of the bill's sponsors, Sen. Christopher Dodd of Connecticut, has warned that the spending freeze "will make it hard to continue to assure quality care for residents of institutions."

'The fallacy in this legislation is that it assumes there is an inverse relationship between [an insutution's] quality and size [illegible]

The fallacy in this legislation is that it assumes there is an inverse relationship between quality and size: big institutions are bad, small facilities or family homes are good. That's simply not the case. Some institutions provide excellent care for the severely disabled at reasonable cost. Some don't.

Forcing institutions to close, without regard for their quality and the needs of their residents, would simply repeat the disastrous policy that was applied to the mentally ill. How many times do we have to make the same mistake?

CABINET FOR HUMAN RESOURCES
COMMONWEALTH OF KENTUCKY
FRANKFORT, KENTUCKY 40621

DEPARTMENT FOR MENTAL HEALTH AND
MENTAL RETARDATION SERVICES
An Equal Opportunity Employer - M/F/H

TO: Dennis D. Boyd
Commissioner

FROM: Charles E. Bratcher C.B.
Division Director

DATE: October 12, 1987

SUBJECT: S.1673

With the implementation of Senate Bill 1673 (Chafee Bill), the Division of Mental Retardation projects the following are conservative cost estimates for our services to the developmentally disabled population:

	6,600	Clients (Unserved MR only)
X	$ 20,000.00	(yearly average cost)
	$ 132,000,000.00	(MR only)
	16,000	Clients (DD eligible non-MR)
X	$ 10,000.00	(yearly average cost)
	$ 160,000,000.00	(DD only)
Projected Total Cost:		
	$ 292,000,000.00	(MR plus DD Clients)
	$ 204,400,000.00	Federal Contribution
	$ 87,600,000.00	State Contribution

The projections of the numbers of mentally retarded clients are based on the Hogan study of the unserved persons with mental retardation. Average yearly expenditures are based on current AIS/MR expenditures and SGF average client cost.

The projections on developmentally disabled unserved are based on federal prevalence estimates. The known MR population in need of services is subtracted from the DD prevalence and the remaining decreased by 50% to account for persons not coming to the service system. The $10,000.00 per person estimates is based on an approximate average cost of minimum services.

CEB:bas

"Protest paper"
Against Senate Bill
1673 (Chafee Bill) aka
Medicaid Home & Community Quality
Services Act of 1987 presented by KARL HUNZIKER, 13 N. Hardee Cir.,
Rockledge, FL 32955

March 31, 1988

I, as a parent of a profoundly retarded son, with over 30 years dealing with his care and a fervent worker for the mentally retarded cause for as many years, have the following objections and observations to make on Sen. Chafee's Senate Bill 1673 and its companion, H.R. 3454, in the House.

This "paper of protest" is also directed at the abandonment of the most severely impaired among our mentally retarded the Department of Health and Human Services has been moving towards in policies being developed. HHS has been listening to developmental disability industralists (the "money-making/grabbing" field who misrepresent and side-step reality in facing up to our national obligation to the most dependent among us).

Sen. Chafee's bill and its comparion, H.R. 3454, are masterfully crafted proposals updated from earlier ones with even more skillfully hidden misconcepts and wording. They would eliminate families from planning processes in care of their loved ones. They would place the fate of mentally disabled under the power of faceless bureaucrats, with state governments being thrust into full-time litigation just trying to enforce its provisions.

Bureaucrats developed the principles set forth in CFLA-1987, the 40-page proposal that mandates phasing out of residential facilities with over fifteen (15) beds, denying families a choice in services. These are goals of this act that are unrealistic and do not face up to the real world we parents, with "hands on" bitter experience, know exist and recognize this act as being so dangerous because of its contents.

This is a renewed effort to move federal dollars away from the over 15-bed residential facilities into a community system that is unstable, grossly deficient in the numbers of skilled professionals needed to provide the type of 24-hour care most severely impaired individuals need.

You in Congress are missing one vital thing you usually wish to deal with on spending. This is a "breakdown" of cost factors. You do not have it, we taxpayers don't have it, I doubt if one exists. That is an unbiased comprehensive study of actual cost factors involved in operation institutions and large (over 15 beds) facilities compared to the "community ones" Sen.

Chafee proposes WITH FIGURES COVERING ALL the necessary services the developmentally disabled can encounter.

Sen. Chafee would have you believe "small is best", that small community placements are less costly than large institutions/programs therefore more cost-effective. Mayeda and Wai, at UCLA, reviewing community and two large public residential facilities, concluded: "The costs of services to developmentally disabled persons in state programs do not differ significantly from the adjusted true costs of services in community settings provided both groups are provided with a full array of need services."

Sen. Chafee expounds small facilities save Medicaid dollars. Facts are the reverse, there is no more costly care than community care when all necessary services are provided.

Medical care in the community is costly (even if there are physicians who will care for the severely retarded in medical emergencies, behavioural problems and lack of speech). There are thousands of communities where this care is not available. There is just as glaring a lack of training and expertise in the care of the ratarded in the community, not to mention the transportation cost and an attendant accompanying the client to get to services even if available.

But large facilities, particularly state operated institutions, have all this available on their grounds without shopping in the community.

MONEY, ladies and gentlemen, is the catalyst in the misleading and unsubstantiated, one-sided "reasoning" expounded by the agencies and bureaucrats responsible for preparing this act of injustice to the members of our society who cannot speak for their rights, who cannot vote, who didn't ask to come into this world in their condition but do deserve fair treatment.

Pressing for this undesirable legislation are national organizations more prone to speak as faceless bureaucrats of self-serving proponents out to grab the all-mighty dollar as vendors, etc., who are not interested in best serving the real interests/needs of the severely handicapped. We parents no longer can look to these organizations, such as the National Association for Retarded Citizens to represent us. The NARC is a group more interested in becoming vendors (operators of community facilities) and have no program for the long-term care of the handicapped who cannot ever hope to be placed in the community.

Many existing group homes and community facilities, if it comes to showdown time, will be more interested in the effect on their profits than in any true concern for care and services to their clients. Here, in Florida, for instance, many of us wonder, even, if it isn't the vendor who is the tail wagging the dog over the state agency allegedly running the show.

Look at these two examples of reported blatant betrayals of parents and the disabled:

In early fall, 1986, Otis R. Bowen, Secretary of Health & Human Services, who allegedly has repeatedly expressed severe and unflattering comments about institutions, held meetings at his office of executive directors of lobbying organizations where he thanked them for leading the way away from out-dated institutions. NO PARENT GROUP is ever heard in his meetings, we're told (count out the Association for Retarded Citizens which is not the voice of the parents it claims to be.

A presidential forum held Feb. 3-5, 1988, at the Mayflower Hotel in Washington, D. C., to examine the national effort to promote maximum community integration of citizens with mental retardation was to highlight success achieved in planning, designing, evaluation and/or implenting community services for the mentally retarded. Was this forum balanced? Not hardily, since it is reported the President's Committee was instructed NOT to invite anyone to speak that supported large residential facilities. Enough said?

Now let's look at some "fine points" of the Chafee Bill:

1. The National Association of Superintendents of Public Residential Facilities for the Mentally Retarded oppose S.1673 as presently drafted. They note that, for one thing, Intermediate Care Facilities/Mentally Retarded (ICF/MRs) could be looking at adjusted reduction of approximately 50-60% in terms of dollars.

(Our personal observation is, also, this so-called "intermediate Care" designation is itself erroneous - what does "intermediate" mean? An interim measure? What we should be talking about is a PERMANENT program, not something to bide us over, from what?)

2. The interdisciplinary team (group of professionals) this bill calls for can exclude from the family any decision making, that to be made by a faceless group of bureaucrats. This can drive a wedge between the disabled's family and the placement situation even though the family has lived with this problem day in, day out. The professionals go home at five, work only five days a week.

3. This bill stresses superimposition on all disabled individuals to achieve independence and self-care. A very extreme position, this is, since there are many severely disabled who NEVER become independent and never exercise self-care skills. My son is one such person. How much better helping them adjust to that fact and help them COPE rather than try to make them develop additional skills they aren't capable of achieving.

4. There are severely disabled who should not be FORCED to interact with a community (itself a discriminatory, intolerant social world setting) because they just can't cope.

5. This bill calls for a case management program as the key to this legislation and of community care. The case manager described in this bill DOESN'T EXIST! There is no one who'd have the education, experience, and skills - nor the 60 to 70 hours a week to put in - and work for the "poverty" wages this bill wants from this "miracle worker".

6. This bill, in its well-couched phraselogy, would phase out the some 230 state institutions that now exist under state management. And, note, that the internal and external enforcement of this bill is a statute that's enforced PRIVATELY by lawyers with their own private interests! Any lawyer can come in and enforce the statute in his state if he can find some way in which some conduct does not conform with this 40-page statute.

This leaves the state governments continually involved in full time litigation trying to enforce the statute even if it has been approved by state heads.

7. Sen. Chafee's objective is still basically the same, his intent has just been more skillfully camouflaged in this new version.

The protective intervention services, listed as a Medicaid finance service, is a duplication of effort whose ulterior motive in this bill is quite obvious. It should be deleted.

8. The senator seems to have forgotten many of the developmentally disabled now in the larger facilities his bill would phase out CAME FROM community small facilities which COULD NOT COPE WITH THEM ADEQUATELY! To ensure the goals of community placement he seeks would create a tremendous and unnecessary paperwork load, It, in turn, by utilizing money for community services of 15 beds or less would skyrocket such care costs, possibly

creating such an overwhelming expenditure on Federal Social Security funds as to raise the question of bankruptcy of that system. Also, this bill does NOT assure there would be quality programming in these community facilities.

9. Dr. Robert J. Zimin of Israel, a psychologist at Chaim Sheba Medical Center near Tel Aviv, on a recent visit to Florida, noted "one of the major fallacies is that community programs are cheaper; in fact, they're more expensive". Another with "hands on" experience heard from.

Here in Florida we have several state-operated institutions, including Gulf Coast Center at Fort Myers where my son has been a client for two years. Prior to that he was at a "for profit" privately operated facility where the care was far inferior (but the owner of the organization operating it and two others in Central Florida could in five years purchase a $260,000 home). So I have had direct, personal contact with two current programs here.

With Florida's burgeoning population situation we actually need another large 400-500 bed state-operated facility in Central Florida, not facing the threat of annihilation of such programs Sen. Chafee and his ilk would force upon us.

In closing let me offer this analogy. Having just retired from many years as a law enforcement officer I draw comparision to our penal institutions where another "class" of our world who can't function in "open" society live. We are familiar with the horrors of some of our old prisons but we have come to a somewhat sane and realistic approach. Would any of us ever suggest we do away with our large prisons and incarcerate our law-breakers in small, local facilities? Oh yes, the comparision is justified, we are speaking of people who can't cope in open society, remember!

Thank you.

Karl Hunziker

Karl Hunziker

The Illinois Association for Persons with Severe Handicaps

13 South Wisconsin · Addison, Illinois 60101

April 5, 1988

Senate Finace Subcommittee on Health
Laura Wilcox, Hearing Administrator
Committee on Finance
Dirkson State Office Building, SD-205
Washington, DC 20510

Dear Laura Wilcox:

On behalf of persons in our state who have severe disabilites, the Illinois Association for Persons with Severe Handicaps is asking for your support of Senate Bill 1673 and its companion bill House Resolution 3454.

"The Medicaid Home and Community Quality Services Act of 1987" is undoubtedly the most important legislation of our time for persons with severe disabilities. Traditionally, funding sources have been constructed in a manner that discourages families of individuals with severe handicaps from keeping their family members at home - most have been forced to admit their percious children and siblings to large congregate care residential facilities. Research has clearly demonstrated that these types of facilities - containing eight beds and over - cannot provide appropriate and humane care due to their very nature. This kind of service delivery for persons with severe handicaps has created a society that believes that individuals with severe handicaps "should be taken care of but do not really belong with the rest of us in our communities."

Passage of this legislation would mean a mandate for adult services, specifically, case coordination; individual and family support services; specialized vocational services; protection and advocacy services; and protective intervention services.

In addition, family support would be provided so that families could keep their family member with disabilities at home. Then...adults with severe disabilities would have opportunities to live in a commuinity based, integrated family scale setting - either at home or in a community group - rather than in a large institution setting.

Those of us who support this and other legislation that will guarantee our citizens with severe disabilities their rightful place in our communities of Illinois are aware that you receive much mail opposed to such legislation. The main sources of opposition are service providers who operate large congregate institutional housing services. These individuals and corporations are protecting their own welfare by actively lobbying against a service delivery that would benefit our citizens with severe disabilities. As you know, this group represents a very powerful lobby. It is because of this powerful lobby that such individuals have succeeded in preventing similar legislation in the past (Chafee's Home and Community Living Amendments). They have succeeded in convincing many parents and family members that the legislation would mean less services for their children.

S 1673 and its companion legislation H.R. 3454 have been carefully constructed to provide safeguards against inhumane "dumping" of our citizens who now reside in institutions. There are checks and balances at every stage and a mandated case management system for each individual. In addition, each individual and his/her family will be offered a choice whether or not to remain in the institution.

Please do not let this one powerful group of lobbyists prevent you from actively researching and supporting this legislation, this is the most important piece of legislation for individuals who are disabled since the passage of Public Law 94-142 which gave all children, regardless of handicap, a right to a free and appropriate public education. As you remember, there were many mislead people opposed to that legislation as well.

Sincerely Yours,

Michael S. Raczak

Michael S. Raczak
President Illinios TASH

STATEMENT FOR THE RECORD

SB 1673 Medicaid and Community Quality Services Act 1987

I, Joseph Jackewicz, want to make a statement for the record, that I oppose that portion of the proposed bill that freezes funds to any facility that has a population of sixteen or more disabled individuals. The proposed bill makes the assumption that my son would be better served in group community homes and I strongly disagree with that premise. My son is now age 33 and I believe that I know his capabilities and limitations as well, if not better than anyone else, and I take strong exception to him being lumped into a group, and automatically generalized that he would be better off in a small community home. What happened to freedom of choice and individual rights?

I am well aware of the full range of services available to the mentally retarded, because I have been active in my community and the State of Delaware for at least 30 years. I was instrumental in establishing along with other concerned parents a trainable school in our area. It took several years for it to become a reality and many years of continued efforts to see it quadruple in size and add recreational services. I also helped establish a sheltered workshop for the handicapped and have been a member of the board of directors for 25 years. I have seen it grow from a one room facility to a workshop with approximately 70,000 square feet, I have also been a member of the Delaware Association for Retarded Citizens for about 25 years and have been involved in issues affecting the mentally retarded in my state. Mental Retardation has been my life for the last 33 years and I feel fully qualified to speak on the issues in the areas of educational, vocational, social and recreational.

I do not believe that de-institutionalization is the answer for every mentally retarded individual and those that desire a choice should not be forced to live in an environment that someone else determines is where they should be. A facility with between 50 and 100 individuals is large enough to hire dedicated professional staff and yet small enough to provide personalized individual care such as birthday parties and special trips. There is a senior citizens apartment in my area that has over 100 senior citizens living in the facility, with many of them subsidized with federal monies from HUD, and no one has told them they can not live in a building that has more than 16 individuals living in the same facility. The mentally retarded like many senior citizens, enjoy participating in many activities within their own social group. With non-handicapped individuals across the United States living in apartments, condominiums, duplexes, and single family homes of their choice, to force the mentally retarded to live in groups of less than 16 or lose benefits, is pure and direct discrimination.

I want to say again, that I oppose any bill that would freeze funding to any facility, existing, or planned, that would provide residential care for the mentally retarded. I believe in quality residential housing for the retarded, with the freedom of choice to live in the type of housing arrangement they feel comfortable in. To effectively and efficiently use the limited federal dollars available, lets not pay the dedicated professional to spend half their time in automobiles driving from one location to another, but lets pay them for providing full time services to the retarded.

Sincerely,

Joseph Jackewicz

Joseph Jackewicz

RD-1 Box 144
Magnolia, De. 19962

Parent
Advocate
Member Delaware Assoc. for Retarded Citizens
Board Member Kent-Sussex Industries (Sheltered Workshop)

April 16, 1988

Ms. Laura Wilcox, Hearing Administrator
U.S. Senate Committee on Finance
205 Dirksen Senate Office Building
Washington, D.C. 20510

Dear Ms. Wilcox:

I, wholeheartedly, support the passage of the Medicaid Home and Community Quality Services Act (S.1673 and R.H. 3454).

This Bill would allow people with developmental disabilities to live in community settings rather than in public institutions. Also, the money provided by the passage of this Bill would improve the services offered to these people.

These people deserve the opportunity to choose community life rather than living in an institution--especially when it is less expensive to live in the community! If these people could be more independent, comfortable and more productive in the community,(for less money) why not give them the opportunity?

Sincerely,

Christina R. Judd

Christina R. Judd
5401 West Coldspring Road
Greenfield, Wisconsin 53220

1102 Stratford Lane
Algonquin, Illinois 60102
April 8, 1988

Laura Wilcox, Hearing Administrator
Committee on Finance
Dirksen Senate Office Building, SD-205
Washington, DC 20510

Dear Ms. Wilcox,

I am writing to you in objection to Senator Chaffee's Bill, S.1673, "The Medicaid Home and Community Service Act of 1987." We are elderly parents (in our 70's) of a severly retarded son who lives in a large church sponsored facility (Bethesda Lutheran Home in Watertown, Wisconsin). It is an excellent home where all his wants and needs are met.

I believe that all facilities should receive funding regardless of their size. The quality of care given should determine funding, not size. A large facility is not always bad, or a small home facility always good.

Retarded people should have the freedom of choice in determining where they will live. If the individual is not capable of making a choice, then parents or guardians should normally have a major say-so.

Larger homes can provide more services and programs which they need than a small group home. Also the cost to build all of these small group homes would be very, very large. Many neighborhoods do not want these group homes next to them. The staffing of all these group homes would be another great problem. It is difficult enough now to find quality staff for existing group homes - where will the additional staff come from for another 15,000 group homes?

Funding should be given to all regardless of where they live - in a small group home or large public private institutions. Some people, especially those with severe physical, behavioral and/or emotional problems, are better and more economically served in a larger facility.

A full spectrum of services should be available to all, as all handicapped have the right to live in the least restrictive setting possible, to receive training to enable them to live more independently, to provide religious instruction, and participate actively in the church of their choice.

There must be adequate time to study Senate Bill 1673 and also to have public hearings.

In behalf of all retarded individuals, please consider Senate Bill 1673 very carefully. Keep funding coming to all and disregard Senate Bill 1673 completely.

Yours truly,

Mrs. Erna Kalsow

April 6, 1988

Senator George Mitchell
Committee on Finance
United States Senate

Dear Senator Mitchell:

This letter represents the written position statement of the Kentucky Association for Retarded Citizens regarding S.1673, the Medicaid Home and Community Quality Services Act of 1987. It is our desire to have this position statement included in the printed record of the hearing on S.1673.

The Medicaid Home and Community Quality Services Act proposes to significantly assist people with severe disabilities by allowing states to receive Medicaid reimbursement for the provision of a broad array of community and family support services. This legislation will also place a qualified freeze on Medicaid payments for large long-term care facilities. In preparing this position statement, we have assumed the members of the Finance Subcommittee on Health have already received testimony as to the need for community based services and how this legislation has been crafted as to assume quality services across the nation. Accordingly, this statement will deal primarily with the fiscal aspects of S.1673 and it's particular impact upon Kentucky.

Over the years states have chosen to utilize Medicaid funds on behalf of persons with developmental disabilities in a variety of ways. There exists a wide variation as to the extent of each states reliance on Medicaid funds as well as the matching ratios between state and federal funds. Consequently, the fiscal impact of S.1673 will likewise vary among states. We are certain the members of the Subcommittee must feel an obligation to understand not only how this legislation will affect their home states but all states as well. We believe the example of Kentucky will help shed some light as to how S.1673 can benefit states which receive a large portion of their institutional funds from the federal government.

Currently Kentucky serves a Medicaid certified developmentally disabled population of only 3,043. According to a study by David Braddock of the University of Illinois at Chicago, in 1986 Kentucky ranked 45th among the states in terms of its share of personal income spent for institutional services. Of the $22,721,950 used to support institutional services in FY 87-88, 72% was provided by the federal government. Since Kentucky is apparently limited in its ability to reduce a relatively small number of institutional beds as well as largely dependent on federal funds to operate large facilities, a freeze on Medicaid funds would, at first glance, seem to be undesirable. In fact, much of the opposition to S.1673 within Kentucky is from parents who fear this legislation will effectively close those states and private ICF/MR facilities upon which they have come to depend.

What most of these concerned parents in the opposition fail to realize is that of the 3,043 Medicaid certified beds which serve people with developmental disabilities, 1,775 are actually in skilled and intermediate care nursing homes. (These figures are according to the Kentucky Department for Mental Health/Mental Retardation Services.) While the desirability of ICF/MR services are certainly to be argued, no advocates of whom we are aware believe nursing homes, ostensibly built to serve an elderly population who have special health care needs, should serve people with developmental disabilities.

A study of the fiscal impact of S.1673 was recently undertaken by the Kentucky Cabinet for Human Resources. The study determined the shortfall of funds resulting from the freeze of federal match with an assumed inflation rate of six percent. The revenue shortfall predicted by the Cabinet would grow to $18,364,665 by FY 92/93. The Cabinet further concluded that without supplimental revenue, this shortfall would result in a reduction of 574 institutional beds. Conversely, however, by applying Kentucky's existing unmatched state funds for community services, community dollars under S.1673 could be leveraged to produce an additional $29,320,107 in federal matching revenue. These funds would more than adequately provide the resources necessary to serve those individuals who formerly resided in such institutional settings as nursing homes in more appropriate community based settings. Moreover, Kentucky would finally be in a position to provide much needed services for the thousands of other Kentuckians with developmental disabilities who are not living in institutions.

In closing we urge you to consider the necessity of Medicaid reform not just for Kentucky but for the nation. Over the years local, state and federal efforts have contributed a great deal of resources toward the establishment of preschool services, manditory special education and supported employment opportunities. It is absurd to have made such a commitment of hope to our young people with disabilities when the lion's share of resouces to assist these individuals as adults are being channeled into institutions.

The Kentucky Association for Retarded Citizens and its members across our Commonwealth strongly urge you to support S.1673.

Sincerely,

Denise M Keene

Denise M. Keene
President

cc: Sen. Wendell Ford
Sen. Mitch McConnell
Rep. Jim Bunning
Rep. Larry J. Hopkins
Rep. Carroll Hubbard Jr.
Rep. Romano L. Mazzoli
Rep. William H. Natcher
Rep. Chris Perkins
Rep. Harold Rogers

THE SECRETARY FOR HUMAN RESOURCES
COMMONWEALTH OF KENTUCKY
FRANKFORT 40621

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MARTHA LAYNE COLLINS
GOVERNOR

E. AUSTIN JR.
SECRETARY

October 28, 1987

The Honorable Wendell H. Ford
The United States Senate
Room 173-A, Russell Senate Office Building
Washington, D. C. 20510

Dear Senator ~~Ford:~~ Wendell

Two bills that would provide Medicaid coverage for community-based services to severely disabled individuals have been introduced in Congress: Senate Bill 1673 introduced by Senator Chafee and its companion bill, HR 3454, introduced by Representative Florio.

The Cabinet for Human Resources has developed community-based services through the allocation of state general fund dollars to the community mental health centers and through our alternative intermediate services waiver program (AIS/MR) under Medicaid. Although resources are not sufficient to meet the overwhelming needs, these efforts are reflective of our commitment to the development of community-based services.

While the Cabinet applauds Congress' attempts to meet the needs of severely disabled persons and recognizes the need for increased funding for community-based services, we cannot support these bills as written. Both bills freeze Medicaid funds going to in-patient mental retardation facilities at current year levels which could result in a 60% decrease in the number of ICF/MR beds in fifteen years as the funds coming to the state fail to keep up with inflation rates.

The bills do not recognize the efforts that Kentucky has made toward deinstitutionalization and provision of community-based services. With only 1203 ICF/MR beds in nine private and public facilities, we have one of the lowest bed-to-population ratios in the nation. In fact, several states of comparable size have two to three times more beds than Kentucky, and some have more beds in one facility than we have in nine.

We believe that severely disabled persons are entitled to a choice which only a full array of in-patient and community-based services can provide. We also believe that the size of a facility and the quality of services provided are not necessarily related and that the phasing out of facilities 16 beds or larger as called for in these bills is neither cost effective nor programmatically warranted.

I urge you to work toward amending these bills so that funding to our present in-patient facilities will not be interrupted and so that we can maintain our current minimal number of ICF/MR beds. Without such an amendment, I would ask that you oppose the bills as they would effectively eliminate the right to choose for many severely disabled persons and could cause a severe economic hardship on the state's fiscal resources.

Sincerely,

E. Austin, Jr.
Secretary

AN EQUAL OPPORTUNITY EMPLOYER M/F/H

THE COURIER-JOURNAL, TUESDAY, OCTOBER 27, 1987

1987 OCT 33 AM 9 36

EDITORIALS

Beyond the open door

THE MOVE to deinstitutionalize the mentally ill — to get them out of big "asylums" and out into the community — was widely acclaimed as an unqualified success in the 1960s and '70s.

Today we know better. Too little money was spent on community treatment programs that were supposed to replace institutional living. As a result, the mentally ill now constitute a large share of the homeless who wander the streets of America's cities.

Despite this, a group of well-meaning but misguided lawmakers in Washington is proposing the same approach for the mentally retarded and physically disabled. Led by Sen. John Chafee of Rhode Island, they are pushing legislation that would squeeze Medicaid funds that support the disabled in public and private institutions.

Much in this bill — the "Medicaid Home and Community Quality Services Act" — is desirable. It would provide federal funds for a wider range of services, including home care, and would help a larger number of the disabled. But to offset the added costs, the bill would freeze funding for institutions with more than eight or nine beds. Eventually, as the cost of living rose, the purchasing power of these funds would shrink, and the institutions would be forced to curtail services or close.

Even one of the bill's sponsors, Sen. Christopher Dodd of Connecticut, has warned that the spending freeze "will make it hard to continue to assure quality care for residents of institutions."

> 'The fallacy in this legislation is that it assumes there is an inverse relationship between [an institution's] quality and size . . .'

The fallacy in this legislation is that it assumes there is an inverse relationship between quality and size: big institutions are bad, small facilities or family homes are good. That's simply not the case. Some institutions provide excellent care for the severely disabled at reasonable cost. Some don't.

Forcing institutions to close, without regard for their quality and the needs of their residents, would simply repeat the disastrous policy that was applied to the mentally ill. How many times do we have to make the same mistake?

GENTELMEN:

I AM HERE TO ASK YOU TO DO SOMETHING POSITIVE ABOUT THE MEDICAID REFORM BILL. OUR MULTI-HANDICAPPED DAUGHTER LOST HER SSI AND MEDICAID BENEFITS BECAUSE WE REFUSED TO LIVE BY RULES AND REGULATIONS WHICH ARE OUT DATED. BECASUE MISSY LOST HER SSI,SHE IMMEDIATELY LOST HER MEDICAID BENEFITS ALSO. MY INSURANCE,THROUGH WORK,PAID FOR AT LEAST 80% AND SOMETIMES 100% OF HER MEDICAL AND DENTAL EXPENSES. ISN'T THAT BETTER THAN PAYING FOR HER EXPENSES PLUS THE REST OF OUR FAMILY'S EXPENSES BECAUSE WE WERE ON WELFARE? WHY IS IT AUTOMATIC THAT WHEN ONE LOSES HIS SSI,HE ALSO LOSES HIS MEDICAID? SHOULDN'T THE TWO BE SEPARATE ISSUES? WHY,WHEN IT COMES TO ELIGIBILITY FOR SSI,AREN'T PEOPLE ALLOWED TO BE QUALIFIED BY THE NET INCOME AND NOT THE GROSS INCOME? ALSO WHY AREN'T THERE ALLOWANCES FOR WHAT THE FAMILY HAS TO PAY FOR THE CARE OF THE CHILD? WHY ARE THERE PROGRAMS THAT ONLY A FEW PEOPLE KNOW ABOUT TO HELP FAMILIES WITH THESE SPECIAL CHILDREN? WHY AREN'T THERE TRAINED SOCIAL WORKERS TO SHOW FAMILIES WHERE TO GO AND WHAT HELP IS AVAILABLE TO THEM? WHY DON'T THESE SOCIAL WORKERS FOLLOW UP ON THESE FAMILIES TO BE SURE THAT THEY ARE GETTING THE HELP THAT THEY NEED? WHY ARE INSURANCE COMPANIES WILLING TO PAY TWICE THE AMOUNT TO KEEP A CHILD IN THE HOSPITAL AND NOT WILLING TO FIND EVERY WAY POSSIBLE TO BRING THAT CHILD HOME? [illegible] WOULD LOWER INSURANCE COSTS AND THE FAMILY COULD TAKE BETTER CARE OF THE CHILD THAN ANYONE,FOR THEY WILL GIVE THE CHILD THE LOVE IT NEEDS. WHAT GIVES A SOCIAL WORKER THE RIGHT NOT TO TURN PAPERWORK INTO [illegible] JUST BECAUSE SHE THOUGHT THAT IS WAS A WASTE OF TIME [illegible] THAT THE CHILD WOULD DIE ANYWAY? WHY ARE PARENTS FORCED TO GIVE THE CHILD UP TO BE PUT INTO INSTITUTIONS OR FOSTER HOMES? WHY IS THE FAMILY FORCED TO [illegible] TO GET THE HELP THAT THEY NEED FOR THAT SPECIAL CHILD? AREN'T OUR AGENCIES SUPPOSED TO HELP KEEP THE FAMILY TOGETHER? WHY DO SOME STATES ALLOW FOR MEDICAID TO PAY FOR SOME THINGS WHEN OTHER STATES WILL NOT?

[illegible] DAUGHTER MICHELLE RENE KUEHN WAS BORN PREMATURELY,WEIGHING ONLY TWO POUNDS. WHEN SHE WAS [illegible] MONTHS OLD,SHE CAME DOWN WITH SPINAL MENINGITIS,CAUSING MASSIVE BRAIN DAMAGE AND HYDROCEPHALUS. A SOCIAL WORKER FINALLY TOLD US ABOUT THE CRIPPLED CHILDRENS PROGRAM. WE FILLED OUT THE PAPERWORK AND TURNED IT INTO HER. AFTER TWO MONTHS,WE FOUND OUT THAT THE SOCIAL WORKER NEVER TURNED MISSY'S PAPERWORK IN BECAUSE SHE THOUGHT THAT IT WOULD BE A WASTE OF TIME. SHE HAD HEARD THAT MISSY WOULD PROBABLY DIE. THIS ACTION CAUSED MISSY NOT TO BE ELIGIBLE FOR SSI AND MEDICAID FOR EIGHT

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MORE MONTHS. NO ONE CAME TO TALK TO US ABOUT OTHER PLACES WE MIGHT GO FOR HELP. AS FAR AS WE KNEW,WE WERE ON OUR OWN. IF A TRAINED SOCIAL WORKER, DEALING ONLY WITH WAYS TO HELP FAMILIES WITH SPECIAL CHILDREN,HAD BEEN THERE HOW MUCH WOULD HAVE BEEN SAVED IN TIME AND MENTAL STRAIN?

WHEN WE MOVED FROM OMAHA,NE. TO COLORADO SPRINGS,CO.,WE NEVER IMAGINED THAT MISSY WOULD LOSE HER MEDICAID. WE CAME OUT HERE BECAUSE OF MISSY'S HEALTH. DOCTORS HAD WANTED TO PUT A TRACHE IN SO IT WOULD BE EASIER FOR US TO CARE FOR MISSY. WE DECIDED THAT IT WAS BETTER TO STAY UP ALL NIGHT AND HOLD MISSY UPRIGHT THAN TO ALLOW THEM TO DO THIS TO HER. WE THOUGHT THAT A CHANGE IN ALTITUDE WOULD MAKE IT EASIER FOR MISSY TO BREATHE. AFTER WE GOT HERE,WE DECIDED THAT MY OLDEST DAUGHTER WOULD QUIT SCHOOL AND CARE FOR MISSY DURING THE DAY SO MY HUSBAND AND I COULD BOTH WORK. WE HAD WANTED A BETTER LIFE FOR ALL OF US AND THE ONLY WAY TO ACCOMPLISH THAT WAS FOR BOTH OF US TO WORK AND DENISE TO CARE FOR MISSY. I DO NOT UNDERSTAND WHY FAMILIES ARE JUDGED ON THEIR ELIGIBILTY BASED ON THEIR GROSS INCOME. THIS IS NOT THE AMOUNT THAT YOU HAVE TO LIVE ON AND PAY OUT FOR EXPENSES. ALSO THERE IS NO CONSIDERATION FOR WHAT THE FAMILY HAS TO PAY OUT TO CARE FOR THAT CHILD AT HOME. FAMILIES THAT KEEP THEIR CHILDREN AT HOME SAVE THE STATE AND FEDERAL GOVERNMENTS THOUSANDS OF DOLLARS BY KEEPING THESE CHILDREN AT HOME. WHY DO INSTITUTIONS GET TAX BREAKS AND SPECIAL CONSIDERATION AND NOT THESE FAMILIES? WE HAD TO PAY $100.00 A WEEK FOR DENISE OR SOMEONE TO CARE FOR MISSY WHILE WE WERE AT WORK.$125.00 A MONTH FOR MISSY'S DIAPERS THAT MY INSURANCE DID COVER BECAUSE THE INSURANCE COMPANY SAID IT WAS NOT A NECESSITY. BUT MISSY WAS TOO LARGE TO FIT INTO BABY DIAPERS AND SINCE SHE HAD NO CONTROL OVER HER FUNCTIONS,IT REALLY WAS A NECESSITY. ALSO THERE WERE CERTAIN THINGS THAT SHE NEEDED EVERY DAY THAT MEDICAID WOULD NOT PAY FOR IN THE STATE OF COLORADO. IN THE STATE OF NEBRASKA,IF A DOCTOR WRITES OUT A PRESCRIPTION FOR IT,MEDICAID WILL PAY FOR IT. IN THE STATE OF COLORADO,IF YOU CAN BUY IT OVER THE COUNTER MEDICAID WILL NOT PAY FOR IT. I DON'T UNDERSTAND WHY THERE ISN'T A GENERAL RULE FOR EVERY STATE ON WHAT MEDICAID WILL PAY. IT TOOK EVERY DIME OF MY CHECK TO PAY FOR THE THINGS THAT MISSY NEEDED,BUT THAT DIDN'T MATTER FOR SHE WAS OUR LIFE. MISSY HAD TO HAVE THE TEMPERATURE IN OUR HOME A CERTAIN DEGREE OR ELSE SHE WOULD GET PNEUMONIA IN THE WINTER AND WOULD HAVE VOMITTING SEIZURES IN THE SUMMER. WHY ARE SOME TOWNS ALLOWED TO TURN OFF THE GAS AND WATER WHEN THEY KNOW THAT THERE IS A HANDICAPPED OR RETARDED CHILD IN THAT FAMILY? IN [illegible] [illegible],THERE WERE FOUR OCASSIONS THAT THIS HAPPENED TO US. THEY WERE [illegible] TO FEAR THAT WE COULDN'T PAY BECAUSE THERE WASN'T ENOUGH MONEY

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TO GO AROUND OR HEAR AN EXCUSE THAT MISSY HAD NEEDED SOMETHING SPECIAL THAT WEEK AND SHE HAD TO COME FIRST.

WHEN WE MADE MORE MONEY THAN SSI ALLOWS,WHICH IS JUST OVER $900.00 A MONTH,MISSY LOST HER MEDICAID AND HER SSI. AT ONE TIME DARRELL AND I HAD TO SEPARATE,HOPING THAT MISSY WOULD GET HER MEDICAID BACK. WE DIDN'T CARE ABOUT THE SSI. WE ONLY NEEDED HELP WITH HER MEDICAL EXPENSES THAT MY INSURANCE WOULD NOT COVER. IT WAS A VERY STRANGE SITUATION. WHEN DARRELL WAS IN THE HOME MISSY GOT HER SSI AND MEDICAID,BUT WHEN HE LEFT AND I ONLY HAD MY INCOME TO DEPEND ON,MISSY WAS NO LONGER ELIGIBLE. THEY ONLY WENT BY WHAT I GROSSED AND NOT BY WHAT I BROUGHT HOME. THEY DIDN'T CARE WHAT WE HAD TO PAY OUT FOR WHAT MISSY NEEDED TO LIVE OR WHAT BILLS WE WERE TRYING TO PAY(WHICH WERE MISSY'S MEDICAL BILLS THAT INSURANCE DID NOT COVER). THEY DIDN'T UNDERSTAND THAT I WOULD WORK OVERTIME BECAUSE MY CHECK WAS BEING GARNISHED FOR BILLS THAT WE COULDN'T PAY.

I WENT TO SOCIAL SERVICES AND BEGGED FOR HELP JUST TO HELP MISSY. I DIDN'T QUALIFY FOR ANY ASSISTANCE BECAUSE I GROSSED TOO MUCH MONEY. AGAIN I WAS JUDGED ON MY GROSS INCOME AND NOT MY NET INCOME OR WHAT IT COST FOR MISSY'S NEEDS. WHEN I ASKED FOR HELP WITH FOOD STAMPS BECAUSE MISSY NEEDED SPECIAL FOOD,I WAS TURNED DOWN. I ONLY WANTED FOOD STAMPS FOR HER. IT DIDN'T MATTER IF THEY HELPED THE REST OF US. MY MAIN WORRY WAS MISSY. I ALSO WAS TURNED DOWN WHEN I ASKED FOR ENGERY ASSISTANCE FOR MISSY. I LATER FOUND OUT THAT THERE ARE HIDDEN PROGRAMS THAT WILL HELP FAMILIES BUT THE SOCIAL SERVICE DEPARTMENT DOESN'T WANT TOO MANY PEOPLE KNOWING ABOUT THEM. THE SOCIAL SERVICES DEPARTMENT WAS AFRAID THAT THE MONEY WOULD RUN OUT. HOW ARE PEOPLE GOING TO KNOW ABOUT HELP IF IT ISN'T MADE AVAILABLE TO THEM? I LEARNED THIS FROM AN ARTICLE THAT THE NEWSPAPER HAD RUN ABOUT MISSY AND ANOTHER ONE THAT WAS ABOUT A FAMILY TRYING TO BRING THEIR CHILD HOME FROM CHILDREN'S HOSPITAL IN DENVER. THE MOTHER WORKED FOR THE SOCIAL SERVICES DEPARTMENT IN COLORADO SPRINGS. SHE SAID THAT SHE WOULD HAVE NEVER BEEN ABLE TO GET THROUGH THE MAZE IF SHE HADN'T KNOWN WHERE TO GO AND WHAT QUESTIONS TO ASK.

THE ARTICLE ALSO SPOKE ABOUT HOW INSURANCE COMPANIES WILL PAY OUTRAGEOUS AMOUNTS TO KEEP A CHILD IN A HOSPITAL BUT WON'T PAY IF THE PARENTS BRING THAT CHILD HOME. THIS PRACTICE KEEPS EVERYONE'S INSURANCE RATES UP. PARENTS CAN CARE FOR THEIR CHILD AT HOME,EVEN THE MOST SEVERE CASES. WE HAD TO LEARN MANY DIFFERENT THINGS IN THE YEARS THAT MISSY LIVED. WE DID OUR VERY BEST TO DO EXACTLY HOW THE DOCTORS SHOWED US. DOCTORS WERE ALWAYS COMPLIMENTING US ON OUR ABILITY. WE TOLD THEM THAT WE WANTED MISSY TO HAVE THE VERY BEST CARE

AND THAT MEANT FROM US TOO. WE LEARNED OUR TASKS OUT OF LOVE AND NOT BECAUSE IT WAS OUR JOB AND SHE WAS JUST ANOTHER PATIENT. WHY WILL INSURANCE COMPANIES PAY FOR ITEMS IN THE HOSPITAL AND NOT FOR THEM ONCE THE CHILD HAS GOTTEN HOME? THE MOTHER IN THE OTHER ARTICLE SAID THAT IT COSTS THE INSURANCE COMPANY OVER $39,000.00 A MONTH TO KEEP THEIR SON IN THE HOSPITAL BUT THEY WOULDN'T PAY THE $19,000.00 A MONTH TO LET HIM COME HOME. HER SON NEEDED SOME ITEMS THAT THE INSURANCE COMPANY PAID FOR IN THE HOSPITAL BUT WOULD NOT PAY FOR AT HOME.

IS IT BECAUSE THEY DON'T FEEL THAT PARENTS CAN'T OR WON'T TAKE AS GOOD OF CARE OF THE CHILD AT HOME? THAT IS BOLOGNEY! DOCTORS TOLD US THAT THEY WISHED THAT THEIR INTERNS WOULD PAY AS MUCH ATTENTION TO THE PATIENTS' PROBLEMS AS WE DID.

IN FEBRUARY OF 1986 WE KEPT TELLING THE DOCTORS AND HOSPITAL THAT MISSY'S SHUNT WAS NOT WORKING. THEY RAN ALL THEIR TESTS AND NOTHING SHOWED UP BUT WE STILL PERSISTED WITH OUR STORY. WE KNEW MISSY AND HOW SHE WOULD VOMIT WHEN HER SHUNT WASN'T WORKING AND HOW SHE WOULD ACT. THE DOCTORS TOLD US THAT OVER 95% OF MISSY'S BRAIN WAS DEAD AND THEY COULD DO NO MORE FOR HER. EVEN THOUGH ONE DOCTOR HAD TAPPED HER SHUNT ONE DAY AND THE NEXT DAY MISSY WAS BACK TO HER OLD SELF, THE DOCTORS JUST KNEW THAT THEY WERE RIGHT. FINALLY AFTER TWO MONTHS OF SEEING MISSY DWINDLE DOWN TO NOTHING BUT BONES,NOT BEING ABLE TO OPEN HER EYES BECAUSE OF THE PRESSURE IN HER HEAD,SCREAMING FROM THE PAIN THAT IT WOULD CAUSE HER WHEN YOU TRIED TO MOVE HER,WE DEMANDED THAT THE DOCTORS DO ANOTHER CAT SCAN. THEY FINALLY FOUND FLUID BUILDING UP ON THE BRAIN. AFTER TWO MONTHS OF PURE HELL FOR US AND ESPECIALLY FOR MISSY,ANOTHER DOCTOR WAS CALLED IN AND HE OPERATED AND THE SHUNT WAS NOT FUNCTIONING. SO YOU SEE, PARENTS CAN TAKE EXCEPTIONAL CARE OF THEIR SPECIAL CHILDREN.

IN CONCLUSION,I WOULD LIKE TO SAY THAT WE NEED TO UPDATE THE REGULATIONS AND RULES FOR EVALUATION FOR SSI AND MEDICAID. MY LITTLE GIRL LOST HER LIFE ON DECEMBER 25,1986,BUT WE WANT OTHER FAMILIES NOT TO HAVE TO GO THROUGH ALL THE PROBLEMS THAT WE DID. FAMILIES WITH THESE SPECIAL CHILDREN LOVE THESE KIDS AND NEED SOCIETY'S PRAISE AND HELP. DON'T FORCE FAMILIES TO GIVE THEIR CHILD UP IN ORDER TO GET THE HELP THAT IS NEEDED. WHY WILL COUNTY AGENCIES GIVE A FOSTER FAMILY FOOD STAMPS,CLOTHING,AND OTHER ASSITANCE TO CARE FOR A SPECIAL CHILD BUT WON'T HELP THE CHILD'S NATURAL FAMILY TO KEEP THAT CHILD AT HOME? WHY WILL AGENCIES PAY FOSTER PARENTS MONEY TO CARE FOR THESE CHILDREN IN THEIR HOMES BUT WILL NOT GIVE SPECIAL CONSIDERATION TO THE NATURAL PARENTS? PLEASE SENATORS,I BEG OF YOU TO MAKE DRASTIC CHANGES AND HELP THESE FAMILIES AND THESE VERY SPECIAL CHILDREN! PLEASE REALIZE THAT THESE CHILDREN ARE LOVE IN ITS PUREST SENSE. WE WERE NOT ASHAMED OF MISSY,WE FELT THAT WE CHOSEN

ONES. SHE TAUGHT US THE TRUE MEANING OF LOVE, COURAGE, DETERMINATION, AND SEEING THE WORLD AND PEOPLE THROUGH ANOTHER'S EYES. IF THE LORD HAD GRANTED US ANOTHER FORTY YEARS WITH MISSY WE WOULD HAVE BEEN GRATEFUL. IF YOU DON'T MAKE CHANGES IN THE MEDICAID BILL, THEN YOU ARE CONTRIBUTING TO THE IMMORALITY OF THE UNITED STATES IN THE LONG RUN. FOR SOCIETY WILL BE PAYING MORE FOR WHOLE FAMILIES TO LIVE ON WELFARE JUST SO THEY CAN GET THE HELP THEY NEED FOR THEIR SPECIAL CHILD.

I AM BEGGING YOU FOR THE OPPORTUNITY TO COME AND TESTIFY AT YOUR HEARINGS. I CAN NOT IN THIS SHORT LETTER TELL YOU OF ALL THE THINGS THAT HAVE HAPPENED TO MISSY AND OUR FAMILY. PLEASE HEAR MY PLEA!

SINCERELY,

Sarah A. Kuehn
1520 Canoe Creek Drive
Co. Springs, Co. 80906
719-576-2675

Hearing Date: Tuesday, March 22, 1988

March 17, 1988

To: Senate Finance Subcommittee on Health, Washington, D.C.
Re: S.1673, the Medicaid Home and Community Quality Services Act of 1987

We are parents of a four year old profoundly mentally retarded (I.Q. below 20 physically handicapped, and profoundly deaf little boy named Douglas. We write you today to share our story with you and to comment upon S. 1673.

Senator Chafee's Bill is a fine attempt at providing more group homes for the mentally retarded. And for the vast majority of the mentally retarded who can appreciate and benefit from a "home setting," this Bill can work wonders. Unfortunately, our son does not fit that description nor does he fall into the 90% of the retarded category who are only mildly retarded, nor the 3.5% of the retarded who are moderately retarded. Our little guy has the unfortunate distinction of falling into the 1.5% of the retarded who are profoundly retarded. These are not the children of the Special Olympics. These are not the children who will grow up to care for themselves, do light housekeeping, and live with minimal supervision in an adult group home. These are the children who are medically fragile and require constant supervision, medical care, custodial care and tremendous support services from allied health personnel such as physical therapy, occupational therapy, respiratory therapy, etc. etc.

In December of 1986, after 2 1/2 years of constant medical crises with our son, we made the painful decision to seek residential placement. We have two older children who deserve the opportunity to lead as normal a life as possible as do we. We were appalled at what we encountered.

In Palm Beach County, HRS (Health & Rehabilitative Services) advised us to look elsewhere because they had no residential facilities at all. Here in Broward County there are two facilities, both ICFMR's. One is called the Pembroke Pines Cluster (28 beds) and the other is called the Ann Storck Center (48 beds). There were no openings and huge waiting lists. HRS in Broward Country tried to discourage us by quoting ghastly statistics such as waiting lists for residential placement of 200! We then looked southward to Miami and found only one facility suitable for our son because of his age, disabilities, etc. This is the Sunrise School, a SUPERB 120-bed ICFMR. We even flew to Orlando and saw a 50-bed facility called Kradle Kare which impressed us as well.

We were discouraged right & left from placement - "well-meaning" social workers and HRS employees telling us that our son belonged at home where he would be in that "home setting" with people who truly loved him. Over and over again we had to explain to these strangers that, sad to say, our son did not know us, would not appreciate our home from theirs, and that our love for him despite his problems was ruining our home life. The constant medical emergencies had made everybody tense.

We continued our battle to find good, nearby placement. We organized a letter writing campaign to Governor Martinez of Florida. He received over 2,000 letters concerning our son and the other 200 families in Broward waiting for residential openings for their children. We uncovered gross mismanagement of our son's case by HRS. We made a stink! We humbled ourselves! We did not care! Miraculously, an opening occurred in Feb. 1987 and our son was placed at the Sunrise School in South Miami last March, 1987. How ironic that your subcommittee is meeting on our son's 4th birthday and just one week short of the 1 year anniversary of his placement at the Sunrise School...here we are still fighting for the rights of profoundly disabled/retarded children, that 1.5% of the retarded population who are generally overlooked in the shuffle of helping the vast majority of the retarded who have much greater potential.

We are delighted that your Bill encourages the opening of more quality group homes for 6-15 clients, but we do NOT feel that this type of setting is best for children such as our son who is profoundly disabled, totally dependent, and medically fragile. To duplicate the excellent medical care, staffing, equipment, and services of the Sunrise School in a tiny, 6-15 bed house, the government would be overspending considerabl It is certainly not cost effective. As for the "home setting," our son - and others at his degree of retardation - do not appreciate the fact that they are in a small house. These ideas satisfy the needs of many advocates and some parents but do not face reality. In actuality, Doug's facility, although 120 beds, is broken down into small units. Our son has one roommate and there are only 10 children in his "suite." There are two other suites similar to his...all three of these suites are for non-ambulatory, medically fragile children coded Federally 8 or 9. The 80 remaining older, ambulatory clients are housed in 8 10-bed "villas." This latter group appears to be the type of children/young adults your Bill is aimed at...higher functioning, with some or a great degree of potential for advancement, independent living, etc.

Your efforts are noble. As stated earlier, the vast majority of the mentally retarded are only mildly retarded and do not even need residential services. They need numerous community-based programs, respite care for their families, and more group homes for the retarded adults whose folks can no longer care for them. Special education programs are finally being expanded thanks to lobbying by advocacy groups, parents, and some caring politicians...much more is needed though.

What concerns us, basically, is that the medicaly fragile, profoundly handicapped child is not best served in a small 6-15 bed house - not only is it not cost effective, but it could be dangerous with poor accountabilit lack of sufficient day programs and equipment, and a lack of medical support

In their haste to close down the 1,000 bed "snake pit institutions" of old, well-meaning advocates of the mentally retarded have - intentionally or unintentionally - prevented the expansion of small to moderate size, high quality residential facilities (a.k.a. "institutions") - that is wrong! There is great need for these facilities and lots more of them!!!

With the ever-increasing expansion of the general population there is a proportionate increase in the birth of the handicapped. Medical science now has the ability to save tiny premies of as little as 1 pound - doctors save drowning victims - unfortunately, these success stories are coupled with those who turn out profoundly disabled. There are badly damaged babies born to the ever increasing drug addict population. And there are handicapped babies born to parents who walk out of the hospital and leave the child behind for the State to take care of. Where are these children to go???

We presently drive 1 1/2 hours each way to bring our little boy home on the weekends - that is not what is popularly called a "community based facility." We were among the "lucky" to find a place that close to home; We were lucky to find a facility which, though not a 6-15 bed house, feels like home to us when we visit...the staff is incredibly friendly, our son's room looks like a college dormitory room, and Douglas is doing the best that can be expected.

The freeze you are proposing on residential facilities over 15 beds is, in our opinion, both unwise and unfair. Fine facilities such as the

Sunrise School in Miami, Ann Storck in Fort Lauderdale, and Kradle Kare in Orlando are doing an excellent job. They should be praised and rewarded for their efforts. They should receive additional funding. The higher functioning clients, to whom yourBill is clearly addressed, can now be moved out into these group homes where they can learn independent living skills, thereby opening up beds in the larger facilities for the medically fragile, profoundly retarded child.

We enclose our son's medical history for your perusal as well as an excellent editorial by Fern Kupfer in Newsweek magazine (1982) and an editorial from the Tampa Tribune (1987) concerning these issues of options for profoundly handicapped children. Finally, we enclose a photograph of our family...we may even resemble yours except for our youngest child who is deceptively normal-looking but irreparably damaged.

In closing, we wish to say that all parents of handicapped children should be able to pick and choose from a wide array of options to fit their personal needs. We would never judge another family for the choices they make concerning their disabled child.Even under seemingly identical circumstances, each family is as unique as their individual family members.

We pray that your committee members will not forget the profoundly disabled minority in your hearings on this issue so that they and their families will also get a fair break in life, finally.

Thank you very much.

Sincerely,

Dr. and Mrs Clifford A. Lakin

Dr. and Mrs. Clifford A. Lakin

5591 N.E. 28th Avenue
Ft. Lauderdale, Florida 33308
(305) 771-9924, 771-9808, 491-1095

5 copies mailed to: Laura Wilcox, Hearing Administrator, U.S. Senate, Committee on Finance, Room SD-205, Dirksen Senate Ofc. Bldg., Washington, D.C. 20510
5 copies mailed to: Ed Mihalski, Minority Chief of Staff, U.S. Senate, Committee on Finance, Room SH-203, Hart Senate Ofc. Bldg., Washington, D.C. 20510
Senator George Mitchell, Committee Chairman
Senator John Chafee, S. 1673 Sponsor, Committee Member
Senator Lowell Weicker, Committee Member

Deadline for submission of written statement: April 19, 1988

DOUGLAS LAWRENCE LAKIN
Born 3/22/84
Plantation General Hospital
Plantation, Florida
NICU Discharge 6/15/84

Diagnosis: Opitz-Kaveggia (A.K.A. FG Syndrome) Syndrome(mental retardation synd
Shortened small intestine
Bilateral hearing loss (profound) I.Q. below 20
Undescended right testis

Surgeries:

1) 3/24/84 (Dr. Subhash Puranik, Plantation General Hspt., Plantation, Fla.)
  - Postop Dx:
    - a) A complete high jejunal atresia w/ apple-peel deformity of distal small bowel being fed thru ileocolic artery
    - b) Prescence of di aphragm type atresia in distal sm. bowel
  - Operation:
    - a) Exploratory laparotomy
    - b) Excision of diaphragm w/ anastomosis in small bowel
    - c) Taper jejunoplasty at the proximal jejunum
    - d) End-to-end anastomosis of proximal jejunum & jejunum below the atresia
    - e) Gastrostomy

2) 4/3/84 (Dr. Subhash Puranik, Plantation General Hspt., Plantation, Fla.)
  - Postop Dx:
    - a) Extensive internal abdominal adhesions
    - b) Necrotic 30 cm. of small bowel w/ nonhealing of anastomosis
  - Operation:
    - a) Exploratory laparotomy
    - b) Lysis of adhesions
    - c) Small bowel resection
    - d) Pleating of the jejunum
    - e) End-to-end anastomosis of small bowel

3) 4/12/84 (Dr. Subhash Puranik, Plantation General Hospital, Plantation, Fla.)
  - Postop Dx:
    - a) Newborn baby w/ status post-surgery for a jejunal atresia with short bowel
  - Operation:
    - a) Insertion of broviac catheter intravenous line by surgical cutdown

4) 6/12/84 (Dr. Subhash Puranik, Plantation General Hospital, Plantation, Fla.)
  - Postop Dx:
    - a) Esophageal stenosis
    - b) Rt. inguinal hernia w/ undescended right testicle
    - c) Lt. inguinal hernia
    - d) Phimosis
  - Operation:
    - a) Attempted esophageal dilatation
    - b) Stage I rt. orchiopexy & rt. inguinal herniorrhaphy
    - c) Lt. inguinal herniorrhaphy
    - d) Circumcision

5) 12/14/84 (Dr. J. R. Chandler, Jackson Memorial Hopsital, Miami, Florida)
  - Postop Dx:
    - a) Profound hearing loss (bilateral)
    - b) Flat tympanograms (bilateral)
  - Operation:
    - a) Bilateral myringotomies

6) 11/8/85 (Dr. Paul Dasher, Holy Cross Hospital, Ft. Lauderdale, Florida)
  - Postop Dx:
    - a) Swollen adenoids
    - b) Chronic otitis media
  - Operation:
    - a) Adenoidectomy
    - b) Bilateral myringotomies

7) 6/17/87 (Dr. Frank Kronberg, Miami Childrens Hospital, Miami, Florida)
  - Postop Dx:
    - a) Swollen tonsils
  - Operation:
    - a) Tonsillectomy
    - b) Bilateral myringotomies

DOUGLAS LAKIN

Additional Hospitalizations:

1) 1984: Broward General Hospital - multiple out-patient esophageal dilations by Dr. Subhash Puranik
2) 11/2-11/17/84: Holy Cross Hospital - admission for upper respiratory distress by Dr. Kamal Taslimi/Dr. Joni Leterman
3) 2/7/-2/9/87: Holy Cross Hospital - admission for possible seizure by Dr. Kamal Taslimi/Dr. Charles Azan
4) 3/12-3/14/87: Holy Cross Hospital - admission for severe dehydration by Dr. Kamal Taslimi
5) 4/1/87: Miami Childrens Hospital - ER visit for severe allergic reaction(mil
6) 4/15/87: Miami Childrens Hospital - ER visit for croup
7) 4/24/87: Miami Childrens Hospital - ER visit for breathing difficulty
8) 5/4/87: Miami Childrens Hospital - brief admission for apnea sleep study
9) 7/22/87: Miami Childrens Hospital - ER visit for pneumonia & diarrhea

Medical Specialty Follow-Up:

1) Milk/dairy allergies - followed by Dr. Douglas Sandberg in Miami 1985-1986
2) Genetic evaluations - Mother had normal amniocentesis 10/27/83
   a) Dr. Paul Benke (Mailman Center,Miami,Florida) - 7/12/84, 7/30/84,10/11/84, 12/6/84
   b) Dr. Mark Steele (Pittsburgh Childrens Hospital,Pittsubrgh,Pa.), 1/7/85
   c) Dr. Murray Feingold(Boston National Birth Defects Center), 4/85 -Ft.Lauderdale
   d) Dr.John Opitz (Shodair Childrens Hspt.,Helena, Montana), 7/85 in Atlanta, Georgia
3) Cardiac - Newborn history of heart murmur; pulmonic stenosis suspected but ruled out as murmur disappeared (Dr.J.Krovetz, Hollywood, Fla.)
4) Neurology - Convulsive seizures noted in-hospital on 4/9/84; EEG & CAT scans were negative; Phenobarbitol prescribed until 9/12/84; followed by Dr. Stuart Brown of Hollywood, Fla.; seen at Pittsburgh Childrens Hospital by Dr. Mark Sher (Ja. 1985); Abnormal NMR study on 7/8/85 by Dr. Bob Kagan in Ft. Lauderdale; Visits to Dr. Stu Brown - 8/23/84, 6/26/85, 1/8/86, 7/3/86, 12/12/86; Following placement at the Sunrise School for the Retard on 3/30/87 Douglas has been followed by Dr. Marcel Deray of Miami Children Hospital; sleep apnea study by Dr. Deray, done at MCH on 5/4/87
5) Vision - 5/29/84 Routine premie eye exam at Plantation General by Dr. S. Feldman
   7/27/84 Eye consultation by Dr. Raanannah Katz in Ft. Lauderdale
   8/10/84 Abnormal VER at Miami Childrens Hospital by Dr. M. Deray
   11/23/84 Visual tracking first noted
   1/85 Evaluation at Pittsuburgh Childrens Hospital by Dr. Milton Pettapie
   Bascom Palmer Eye Institute in Miami - Dr. John Flynn - seen 4/16/85; 10/11/85; 9/19/86; 7/21/87
6) Auditory -
   7/23/84, 10/8/84 - normal brain stem studies at Easter Seals in Ft.Laud.
   12/5/84 - abnormal brain stem at Easter Seal
   12/6/84 - abnormal brain stem at Jackson Memorial Hspt.
   12/14/84 - bilateral myringotomies at Jackson by Dr. J. Chandler
   11/8/85 - bilateral myrinogotomies/adenoidectomy at Holy Cross by Dr.Paul Dash
   6/17/87 - bilateral myrinogotomies/tonsilectomy at Miami Childrens Hspt. by Dr. Frank Kronberg
7) Orthopedic -
   2/7/85 Broken Right femur - followed by Dr. Allen Watson at Holy Cross
8) Multi-specialty evaluation -
   Jan. 1985 - Pittsburgh Childrens Hospital

Family Background:

Father: Dr. Clifford Lakin (born 3/7/43) - in good health
Mother: Arlene S. Lakin (born 9/1/47) - in good health
Brother: Gregory (born 4/25/76) - in good health
Sister: Cara (born 2/10/81) - in good health

2/7/87	Seizure? Admit to Holy Cross Hospital, Ft. Lauderdale, Fla.
3/12/87	Stomach virus/dehydration Admit to Holy Cross, Ft. Lauderdale,Fl.
3/30/87	Placement at Sunrise School for the Retarded, Miami, Florida
4/1/87	Allergic reaction to milk cereal/ Miami Childrens Hspt. ER
4/15/87	Croup/ Miami Childrens Hspt. ER

	Rx: Extendryl 5 cc 4 x a day Pediazole 5 cc c 6 hrs. Benadryl 5 cc c 8 hrs. prn Poly-Vi Flor drops w/ iron 1cc po
4/20/e7?	Dr. Gupta (pulmonary pediatrician) 1-665-3506 sleep apnea
4/21/87	Start cardiac monitor at Sunrise
4/23/87	Lt. otitis media Dr. Frank Kronberg (ENT) 1-595-3506 Lance rt.preauricular sinus cyst Rx: T & A; long-term bilateral ear tubes
4/24/87	Respiratory distress/Miami Childrens Hspt. ER
4/24/87	Dr. Paul Dasher(ENT- Ft. Lauderdale) - agrees w/ Dr. Kronberg Dr. Fernandez in Miami does palito-pharyngealplasty w/ temporary tracheostomy
4/24-4/27	Home Visit
4/27/87	Sunrise HAB Plan meeting
5/4/87	Admit to Miami Childrens Hspt.(Dr. Gupta) for sleep/apnea study
6/15-6/18/87	Admit to Miami Childrens Hspt.(Dr. Kronberg) for tonsillectomy and bilateral myringotomies on 6/17/87
7/22/87	Miami Childrens Hospital ER - pneumonia, diarrhea
3/8/88	Miami Childrens Hospital ER - bilateral otitis media (severe)

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Institution Is Not a Dirty Word

MY TURN/FERN KUPFER

I watched Phil Donahue recently. He had on mothers of handicapped children who talked about the pain and blessing of having a "special" child. As the mother of a severely handicapped six-year-old boy who cannot sit, who cannot walk, who will be in diapers all of his days, I understand the pain. The blessing part continues to elude me—notwithstanding the kind and caring people we've met through this tragedy.

What really makes my jaws clench, though, is the use of the word "special." The idea that our damaged children are "special," and that we as parents were somehow picked for the role, is one of the myths that come with the territory. It's reinforced by the popular media, which present us with heartwarming images of retarded people who marry, of quadriplegics who fly airplanes, of those fortunate few who struggle out of comas to teach us about the meaning of courage and love. I like these stories myself. But, of course, inspirational tales are only one side of the story. The other side deals with the daily care of a family member who might need more than many normal families can give.

Stoicism: Parents who endure with silent stoicism or chin-up good humor are greeted with kudos and applause. "I don't know how you do it," the well-wishers say, not realizing, of course, that no one has a choice in this matter. No one would consciously choose to have a child anything less than healthy and normal. The other truth is not spoken aloud: "Thank God, it's not me."

One mother on the Donahue show talked about how difficult it was to care for her severely brain-damaged daughter, but in the end, she said serenely, "She gives much more than she takes from our family." And no, she would never institutionalize her child. She would never "put her away." "For she is my child," the woman firmly concluded as the audience clapped in approval. "I would never give her up."

Everyone always says how awful the institutions are. Don't they have bars on the windows and children lying neglected in crowded wards? Aren't all the workers sadists, taking direction from the legendary Big Nurse? Indeed, isn't institutionalizing a child tantamount to locking him away? Signing him out of your life forever? Isn't it proof of your failure as a parent—one who couldn't quite measure up and love your child, no matter what?

No, to all of the above. And love is beside the point.

Our child Zachariah has not lived at home for almost four years. I knew when we placed him, sorry as I was, that this was the right decision, for his care precluded any semblance of normal family life for the rest of us. I do not think that we "gave him up," although he is cared for daily by nurses, caseworkers, teachers and therapists, rather than by his mother and father. When we come to visit him at his "residential facility," a place housing 50 severely physically and mentally handicapped youngsters, we usually see him being held and rocked by a foster grandma who has spent the better part of the afternoon singing him nursery rhymes. I do not feel that we have "put him away." Perhaps it is just a question of language. I told another mother who was going through the difficult decision regarding placement for her retarded child, "Think of it as going to boarding school rather than institutionalization." Maybe euphemisms help ease the pain a little bit. But I've also seen enough to know that institution need not be a dirty word.

Mothers of handicapped children talk about their special pain and blessing. The blessing part eludes me.

The media still relish those institution horror stories: a page-one photo of a retarded girl who was repeatedly molested by the janitor on night duty. Oh, the newspapers have a field day with something like that. And that is how it should be, I suppose. To protect against institutional abuse we need critical reporters with sharpened pencils and a keen investigative eye. But there are other scenes from the institution as well. I've seen a young caseworker talk lovingly as she changed the diapers of a teen-age boy. I've watched as an aide put red ribbons into the ponytail of a cerebral-palsied woman, wipe away the drool and kiss her on the cheek. When we bring Zach back to his facility after a visit home, the workers welcome him with hugs and notice if we gave him a haircut or a new shirt.

The reporters don't make news out of that simple stuff. It doesn't mesh with the anti-institutional bias prevalent in the last few years, or the tendency to canonize the handicapped and their accomplishments.

Survival: This anti-institutional trend has some very frightening ramifications. We force mental patients out into the real world of cheap welfare hotels and call it "community placement." We parole youthful offenders because "jails are such dangerous places to be," making our city streets dangerous places for the law-abiding. We heap enormous guilt on the families that need, for their own survival, to put their no-longer-competent elderly in that dreaded last stop: the nursing home.

Another danger is that in a time of economic distress for all of us, funds could be cut for human-service programs under the guise of anti-institutionalization. We must make sure, before we close the doors of those "awful" institutions, that we have alternative facilities to care for the clientele. The humanitarians who tell us how terrible institutions are should be wary lest they become unwilling bedfellows to conservative politicians who want to walk a tight fiscal line. It takes a lot of money to run institutions. No politician is going to say he's against the handicapped, but he can talk in sanctimonious terms about efforts to preserve the family unit, about families remaining independent and self-sufficient. Translated, this means, "You got your troubles, I got mine."

Most retarded people do not belong in institutions any more than most people over 65 belong in nursing homes. What we need are options and alternatives for a heterogeneous population. We need group homes and halfway houses and government subsidies to families who choose to care for dependent members at home. We need accessible housing for independent handicapped people; we need to pay enough to foster-care families to show that a good home is worth paying for. We need institutions. And it shouldn't have to be a dirty word.

Fern Kupfer is the author of "Before and After Zachariah."

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A Cry for Help

Catastrophic illness is usually associated with the elderly, or people in their middle years confronted with impossible expenses. The very young can fall into this category also, and the parents of these youngsters find their resources taxed to the limit, and beyond, to provide adequate custodial care and medical needs.

They also discover that their lives have been severely circumscribed by the presence of a handicapped child in the home, but their options are strictly limited. Deinstitutionalization is a long word invented by legislators, not to eradicate the "snake pits," but to balance budgets by closing centralized facilities designed to house the mentally retarded and emotionally ill. The occupants, so reasoning went, would be returned to their separate communities and the tender, loving care of friends and neighbors.

It was sound philosophy as far as it went, but it didn't go very far. Few communities were prepared to receive the overflow from the state's mental institutions and many middle-aged parents found themselves suddenly responsible for a mentally retarded young adult possessing the physical attributes of a professional wrestler and the social accountability of a 3-year-old. Many former occupants of the mental hospitals were housed in cheap welfare hotels, while others took up residence among the "street people."

Meanwhile, the parents of handicapped youths are largely left to fend for themselves as best they can. A Fort Lauderdale couple explained, "In Florida, young disabled children are not being placed in state facilities due to a funding moratorium. Private facilities for young children without major medical involvement start at about $20,000 a year. Existing facilities are not being expanded; new facilities are not being built because of a lack of funding."

And to complicate matters still further, neighborhoods fight the establishment of group homes. Against this background, the old, institutional concept doesn't look so bad, after all.

What is to be done? Fern Kupfer, the mother of a profoundly handicapped boy and author of the book "Before and After Zachariah," has declared:

"What we need are options and alternatives for a heterogeneous population. We need group homes and halfway houses and government subsidies to families who choose to care for dependent members at home. We need accessible housing for independent handicapped people; we need to pay enough to foster-care families to show that a good home is worth paying for. We need institutions. And it shouldn't have to be a dirty word."

We also need an aware public and general sensitivity to a difficult problem. Catastrophic illness can strike at any age, as devastatingly for the very young as for the very old, and equally distressing for those caught in the middle — the children of the elderly and the parents of the children.

Tampa Tribune

April 8, 1987

STATEMENT SUBMITTED TO THE UNITED STATES SENATE COMMITTEE ON FINANCE REGARDING THE MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT OF 1987

(SENATE BILL 1673)
BY
SANDRA S. GARDEBRING, COMMISSIONER
DEPARTMENT OF HUMAN SERVICES
STATE OF MINNESOTA

State of Minnesota
Department of Human Service
Human Services Building
444 Lafayette Road
St. Paul, Minnesota 55155

I. INTRODUCTION

The State of Minnesota has historically provided extensive services for children and adults with severe disabilities. In addition to traditional long-term care services, the State has developed services in less restrictive settings such as Semi-Independent Living Services for adults with developmental disabilities, a Family Subsidy Program for children with developmental disabilities, alternative care grants for persons who are elderly, and a variety of home and community-based waivered services. The Medicaid Home and Community Quality Services Act, S.1673, embodies many values which are consistent with Minnesota's efforts to provide persons with severe disabilities more normalized living environments, individualized services, and the opportunity to improve their capacity for independence and personal competency. S.1673 supports, and does not supplant, the natural home — a value strongly reinforced by many of Minnesota's policies.

Minnesota was among the first states to use Medicaid funds to serve people with mental retardation or related conditions. We were one of the first states in the nation to develop Intermediate Care Facilities for the Mentally Retarded (ICFs/MR) as part of our State Plan to create community residential service alternatives. Use of Medicaid funding has enabled our state to reduce the population of persons with mental retardation who are in state institutions (Regional Treatment Centers) from over 6,000 in the 1960's to less than 1,600 today.

Based on our experience, we have been able to draw some important conclusions regarding the merits of various methods of service delivery. For example, we have learned that the extensive use of ICFs/MR leads to service costs that are high. In 1987, the costs for Minnesota of the ICFs/MR programs alone was approximately $230 million. However, a number of individuals who are eligible for service in ICFs/MR can be served equally well using less costly alternatives such as home and community-based services under the Medicaid Waiver program.

Minnesota has found it possible to move many individuals from our state and private ICFs/MR, to more independent settings under our Home and Community-Based Services Waiver and to demonstrate both an increase in service appropriateness and cost reduction. People were often placed into our large state institutions from their family homes and can be returned directly to their homes or home like settings if sufficient support services are made available to their families or residential staff. For example, 60 of the 209 children and adults moved from our regional ICF/MR treatment centers last year have moved directly home or into home-like settings under our Waiver. We continue to identify individuals for whom such a move is possible. A January, 1988 analysis of client needs in our regional treatment centers indicates that at least 259 of the people still in these ICF/MR settings could be served in home and community-based services. The number of persons residing in our community ICFs/MR who could move to home and community-based services is much larger.

Minnesota's model Home and Community-Based Waiver for medically fragile/technology assisted individuals has repeatedly demonstrated that the most medically fragile people can be cared for in their own communities rather than in an intensive care unit of a hospital. Not only can they be cared for in their own homes, but their physical condition improves and they are able to do things that their physicians believed to be impossible.

For example, Patrick is a child who is ventilator-dependent. He spent the first three and a half years of his life in an Intensive Care Unit of a hospital. He would still be there today if not for the Waiver. Under the Waiver, he can live at home with his mother and attend school with his peers. His mother receives the nursing support she needs to manage his care at home and at school.

Stories similar to Patrick's have been repeated throughout the state. Fortuntely, there are not a large number of similarily technology dependent individuals. However, modern technology has saved the lives of many premature infants and severe accident victims. If we are willing to save these individuals, we must also be willing to support them and their families with the services that they need and allow them to live as normal a life as possible.

Despite the demonstrated success of community placements, fiscal disincentives to "non institutional" settings have existed since the inception of Title XIX funding and continue to exist today. Even the Home and Community-Based Services Waivers, which are an excellent alternative, do not allow movement of enough individuals to community services. Waivers are often viewed by parents and providers as temporary, due to Health Care Finance Agency's (HFCA) authority to approve, deny, terminate and/or renew the State's Waivers. States are required to demonstrate the services will be cost neutral as part of a complicated formula which is difficult to develop and which must be approved by HCFA of the Department of Health and Human Services. However, more traditional "institutional" services are included as a portion of a state's Medicaid Plan. Revisions to each state's Medicaid Plan are much less complicated that applications for waivers and are more within the control of each state. The stability of state plan services and ease of administration favor services that can be developed and supported using that mechanism. Thus, the system still seems to favor medical, institution-based services rather than home and community-based services. We believe the provisions of S.1673 are essential to further movement toward home and community-based services and therefore strongly support the bill. Rather than comment on each provision we would like to highlight a few provisions we feel are key to the provision of services in Minnesota.

II. SPECIFIC PROVISIONS

A. **Provision of services based on need.** We strongly support the provisions of S.1673 which enable us to provide service based on need. Several years ago, the parents of a ten year old child called Minnesota's Department of Human Services to inquire about facilities which could serve their daughter. They wanted to keep her at home, but were told by the county case manager that money was not available and that the only environment available where services could be funded and provided was a regional treatment center (large ICF/MR). After visiting the regional treatment center the parents decided instead to keep their daughter at home. Shortly thereafter, the daughter ran away from home, was sexually assaulted, and was subsequently placed in a regional treatment center. After two years there, Minnesota was able to use the Home and Community-Based Services Waiver to develop a foster home for the adolescent. She continues to live in that home today, succcessfully attending school, frequently visiting her parents at home, and vacationing with her parents. Obviously, this child experienced two years of unnecessary institutionalization and removal from her community. Making family support services available, based on need rather than on an arbitrary formula which is linked to existing service costs, would often prevent unnecessary institutional placements and unnecessary expenditures required for these placements. S.1673 would enable states to determine children under 18, living at home, eligible for services based on the child's income and resources regardless of the income of other family members in the same way we determine elegibility for services n our large ICFs/MR. This would eliminate an unintended bias toward ICF/MR placement where parents can place their children into our large ICFs/MR and, except for a limited fee schedule, these parents are relieved totally of the costs of their child's care.

B. Inclusion of case management in the array State Plan services. Minnesota and other states have been using case mangement services to provide for the individual service planning and oversite necessary to ensure quality services. Consumers are often overwhelmed by the complexity of program and eligibility requirements. They may have trouble accessing services and selecting the most appropriate services. This often results in a delivery system which does not target resources in a way that assures people receive what they actually need, no more and no less. S.1673 would include case management and an Individual Habilitation Plan as part of the required array of services, a position which Minnesota supports.

C. Provision of service options for states. The Medicaid Home and Community Quality Services Act allows states to have more flexibility to choose from the available service options those services which the state determines to be necessary and appropriate. If there is one generalization that can be made about people with disabilities, it is that they are not a homogeneous group about whom many generalizations apply. Similarly, each state has a unique set of circumstances within which it must operate. Establishing a core set of required services, but allowing flexibility in selecting other optional services, reflects an appreciation for differences in state needs and resource availability.

D. Elimination of reapplication process for waivers. Current HCFA regulations require states to use an arbitary "cost effectiveness" cap and reapply at the end of each Waiver period. This policy has the effect of forcing state agencies to devote sizable resources to the process of preparing applications, computing formulas, and repeatedly defending the legitimacy of their requests. S.1673 eliminates the "cost effectiveness" computing formula cap and the need to apply and re-apply for waivers to provide services.

E. Inclusion of improved quality assurance mechanisms. As individuals move from institutional settings into small dispersed living arrangements, we have been impressed with how they benefit from these new living situations. Their parents, advocates, and interested citizens often share success stories with us. Neighbors, church members, school mates, and other community residents — bus drivers, business people, scouts — provide an informal network of friends who safeguard the quality of life for people with disabilities. However, there is a need for formal quality assurance mechanisms to oversee a system serving such a vulnerable group of individuals. We are supportive of the requirement contained in S.1673 for such a system.

F. Simplification of administrative processes and inclusion of administrative costs. Administratively, S.1673 provides more stable funding and simplifies the administration of home and community services. It also includes federal financial participation (FFP) for the administrative activities required by the legislation.

III. SUMMARY

Jason, who is five years old, lives in rural Minnesota. Two years ago Jason fell into a swimming pool and wasn't discovered for 10 - 15 minutes. He has all the medical labels that would classify him as among the most handicapped of children living in any institution. He no longer walks, can't talk, may or may not be able to see, and clearly does not respond to his world the way a child his age normally would. His parents have been struggling to get through the anguish of what's happened, to find the strength to support each other and keep the family intact, while at the same time trying to obtain services for their son. Luckily, they were able to get home and community-based services from Minnesota's waiver to support their efforts as a family. Unfortunately, other children and their families have not been so lucky. They may live in a state which does not have an approved home and community-based waiver services waiver or where the services under the program are so severely limited that their parents are left with no choice but to place the child out of their home.

Federal and state legislation have consistently moved in the direction of community services, however, funding has not always followed. The value of providing support for families has been expressed in concept, but it has not always been backed up by the allocation of resources to support the concept. Why will we pay thousands for institutional care, but not hundreds for home care support?

The Home and Community Quality Services Act is not, as some have suggested, an attack on traditional models. It does not force states to close existing institutions. But it does create a holding pattern for the costs of such care to allow us to re-direct funding in a manner consistent with our stated policy of supporting people in their own homes and community. This legislation allows individuals and their families decide where they will receive needed services.

All of the major organizations representing citizens with developmental disabilities are in favor of passage of this bill. The involvement of so many key stakeholders presents a high degree of willingness to work together in the difficult implementation phase which accompanies any significant piece of legislation. This support will be particularly helpful in the five year planning process.

There are, of course, implementation questions that need to be addressed regarding this bill. The information tracking system and quality assurance provisions are both important, but sufficient time must be provided to allow states to come into compliance. HCFA's sanction authority will need to be established by Congress. In addition, the public hearings required to develop a plan will have some costs associated with them and we will need to consider how to deal with that issue.

Nevertheless, this legislation addresses issues in a humane way and targets money were it is really needed; to establish home and community-based services individuals and their families. Minnesota strongly advocates for passage of S.1673. It will help us to answer the questions parents and family members have been asking for years: "What happens if we are unable to care for our child or relative?" "Where does my child go after special education?" "Why do I have to be impoverished in order to receive supportive services?" This bill gives us freedom to allow for more normal living, working, and leisure time alternatives for persons with disabilities. Hopefully it will do so in a way that is not prescriptive or simplistic in assuming that all people require the same things.

Mr. & Mrs. Robert H. Maurer
10,612 Royal Chapel
Dallas, Texas 75229

April 2, 1988

Laura Wilcox, Hearing Administrator
U.S. Senate Committee On Finance
U.S. Senate Office Building
205 Dirksen, Room S-D-205
Washington, D.C. 20510

Comments On S. 1673, "Medicaid Home and Community Quality Services Act of 1987

Dear

Our severly mentally retarded son Paul K. Maurer has resided in Texas State Schools for 21 years. We are very supportive and thankful for State Schools. We feel that State Schools offer the most appropriate environment possible for our son. A home or community environment, instead of an institution may be appropriate for handicapped individuals who have a lesser degree of mental retardation than the severly and profoundly retarded. Even so, it appears to us that it would be more economical to have the State Schools act as a headquarters to still provide many needed services.

This is Senator John Chafee's third attempt to curtail or elimanate medicaid funding from State Schools. We strongly urge that the provision in the Bill that there be an immediate freeze on medicaid funding at the current level for State Schools be eliminated. If the proposed cap were to become law, no medicaid funding would be available for new State Schools and existing State Schools would not receive an increase in medicaid funding for any purpose.

For some years now State School admission has been closed in many cases for retarded individuals. Our hearts go out to the parents of profoundly and severly mentally retarded individuals in these cases, for some 21 years ago it took us a long time before our son was accepted into the State School because of the long waiting list.

Sincerely,
Robert H. Maurer Janell F. Maurer
Robert H. Maurer Janell F. Maurer

ROSALIND
MERRITT
I N C
Interior Design

March 16, 1988

Ms. Laura Wilcox
Hearing Administrator: US Senate Comm. of Finance
Room #SD-205
Dirksen Senate Office Bldg.
Washington, DC 20510

Re: #1673 Senate Bill: Medicaid Home & Community Quality Services Act of '87

Dear Ms. Wilcox:

I am writing on behalf of the 1.5% of the medically fragile and profoundly retarded citizens of our country who cannot speak for themselves. The Senate Bill #1673 which is going before the subcommitte on Tuesday, while although it is extremely beneficial to the great majority of retarded citizens, does a disservice to the profoundly retarded who cannot fend for themselves. If this bill cuts aid to those larger facilities (greater than 6-15 residents), then these children will be without adequate care which they so desperately need. They need respiratory therapy, occupational therapy, and constant medical attention for their frequent medical crises, which only a larger facility can handle at reasonable cost.

The families of these children will have to suffer if they cannot place the profoundly retarded into an adequate facility. As it is, at some very well-run homes, the placement waiting list reaches into the hundreds for occupied beds which may number in the tens. If the bill can somehow be re-worded such that these beds will become free of the mildly retarded (those who are teachable and can function in the smaller homes of 6-15 beds) to enable the severely disabled ones to have adequate care, then it will be a much fairer one for those whose cases have no where else to go.

Sincerely,

Rosalind Merritt

Rosalind Merritt, ASID

ROSALIND MERRITT INC. • 11537 S.W. 84th STREET • SUITE C • MIAMI, FLA. 33173 • 305-271-2157

TELEPHONE: 504/733-2874

The Magnolia School, Inc.

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MICHAELLE P. WYNNE

April 12, 1988

Committee on Finance
United States Senate
205 Dirksen Building
Washington, D.C. 20510

Dear Senators:

We, the Parents, Friends, Faculty and Staff of Magnolia School, have specific objections to Senator Chafee's Bill S.1673 as it now stands. The Bill, S.1673, called "Medicaid Home and Community Quality Services Act of 1987", has many good features, and we support its general purpose of helping retarded citizens live more independently and participate more fully in community life. We also believe it has some weaknesses, and could have a dramatic adverse impact on the lives of many of our retarded citizens.

The Bill calls for a time schedule requiring any retarded person living in a facility of more than 15 beds to be transferred to a group home of nine beds or less. This feature, combined with the freezing of funding for facilities of 16 or more beds, would spell the end of such facilities. Many are operated by private foundations and provide excellent physical and emotional care for their patients.

Our existing system provides an adequate range of choices for those whose loved ones suffer from disabilities. Despite the good intentions of many, including Senator Chafee, federally mandated directions such as those provided by S.1673 will only serve to limit those choices.

We need your help on what we believe:

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Page 2

1. Quality, not size, should be the criteria for all facilities. So long as facilities educate their residents, give them good care and prepare them for more independent living, size should not be a factor.

2. Federal policy should not "rob Peter to pay Paul". The Chafee Bill takes money from residents in larger facilities and gives it to those who live in their own homes or in group homes.

3. Financial assistance should be limited to those who cannot afford the services they need. As Abrahma Lincoln said, government exists to do for people that which they cannot do for themselves. The Chafee Bill would provide funding for all disabled individuals who cannot earn a living, even for those who parents are millionaires.

4. Retarded people should have freedom of choice in determining where they will live. If the individual is incapable of making a choice, then parents or guardians should normally have the major say-so.

5. Residents of public and private facilities should have equal access to the financial help they need. Living in one or the other should not make them lesser citizens.

6. Some people, especially those with severe physical, behavioral and/or emotional problems, are better and more economically served in a larger facility.

7. A full spectrum of services should be available, including family assistance (if needed), foster care, group homes, vocational training, intermediate and skilled care facilities, and larger institutional settings.

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8. All handicapped people have the right:

   --to live in the least restrictive setting possible,
   --to receive training to enable them to live more independently,
   --to receive religious instruction and participate actively in the church of their choice.

We earnestly solicit your support in seeing to it that this Bill receives adequate scrutiny by the Senate, and hope that you will see your way clear to consult with a broad range of representatives from the private as well as public facilities before taking a position on this bill.

Therefore, we wish to stand as opposing the passing of Chafee Bill (S.1673) and Florio Bill (HR3454), as they are not in the best interest of the Mentally Retarded.

Sincerely,

THE MAGNOLIA SCHOOL, INC.

Joan R. Turcotte

Joan R. Turcotte
Parent of Mentally Retarded Son
Executive Director of Magnolia School

JRT/skg

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April 12, 1988

Mr + Mrs Anthony DiMartino Parents of Retarded Son
Mr + Mrs John Harding " " "
Mr + Mrs Charles K Davenport " " "
Mr + Mrs Charles E Davenport " " "
Mr + Mrs Elton M. Foster
Mr + Mrs Cecil Bostick
Mr. & Mrs. Rlelore Sylve Jr.
Mrs Bernadette Pinet
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Jeanette Casi Social Services Coordinator
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Diane Richardson Bookkeeper
Alma H. Hewitt - Clerical
Barbara Hartzheim - Education Secretary
Mary A. LeBlanc - Teacher
Mary S. Leonard - Teacher Assist.
Joan W. [illegible] - Teacher Assistant
Julie Frech - assistant
Valerie C. Smith Spec. ed teacher
[illegible] Sp. Ed Teacher
Cecelia H. Herrera Teacher Assistant
Marguerite Fanguy
Pam Maynard - assistant
Mary McDuff - asst.
Theresa B. Kurz Asst.
Charlene Boudreaux - teacher

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April 12, 1988

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Mary McDuff - asst.
Theresa B. Kunz Asst.
Marlene Boudreaux - teacher

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Jacqueline Windstein

Brenda Ferger

E. Mackenroth

Sandra K. Gill, Secretary/Records Person

Jeffery D. Helmstetter Principal

Barbara C. Rivero Teacher

Yvette W. Vincent Teacher

Tammy S. McDuff Teacher

Rosalie S. Wolfe Teacher

Linda B. Fitch - Bookkeeper

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Tues., April 5, 1988

Committee on Finance
United States Senate
205 Dirksen Building
Washington, D.C. 20510

Dear Committee Member:

I am writing to you to ask your support in opposing Chafee Bill (S1673) As the sister of one of the clients at Magnolia School in New Orleans (Jefferson, LA), I feel that it would be a tragedy to see such a fine facility closed.

Let me give you a little background. Magnolia is a school for the mildly mentally and emotionally handicapped, a description which can be quite misleading. While it is true that all of the clients at Magnolia are able to feed themselves, and speak so that they can be understood, this is about all of which many of them are capable. My brother Hewitt for instance, in addition to his mental limitations, is epileptic and also has mental and emotional disorders which have required medication and counseling on a regular basis since 1976, or for over 12 years. He is incapable of functioning in an unsupervised environment.

Until 1976 Hewitt was cared for at home by my parents. In his earlier years he attended public school in a special education program. Later he commuted to the Southwest State School in Iota. This was satisfactory for a time, but as he got older, his mental and emotional state worsened. (Hewitt is now 40 years old.) Many different things were tried but all unsuccessfully. Finally he suffered a complete mental breakdown and spent over six weeks under psychiatric care in a mental hospital. At that time we realized that we could not meet his needs at home, and we were fortunate enough to locate Magnolia. There he has done very well, and great efforts have been made to regularly reaccess, re-evaluate, and readjust his program. How could the needs of a person such as Hewitt be met if facilities such as Magnolia are eliminated?

Home care is not the answer for many reasons. First of all, my father is now deceased, and my mother is elderly and barely able to care for herself. I have a husband, job, and family and my own responsibilities; there are no other brothers or sisters. There is no way we can devote the time and attention to Hewitt that he needs.

Secondly, we do not have the special training or the resources to care for Hewitt at home. Can you imagine the traumatic experience we all suffered when he began threatening my parents, making harrassing phone calls to friends and neighbors, pacing the floor at night, throwing his food in the garbage, etc. At Magnolia Hewitt has found a place where he fits in, where the pressures are not more than he can handle, and where he is kept busy in a highly structured program that provides him with security. Hewitt is not at Magnolia because we wanted to get rid of him or our responsibility. He is there because we could not meet his needs and the staff and personnel at Magnolia can to a much greater degree. Many of the other clients at Magnolia are in the same or a similar situation. Now all of this is being threatened by Chafee Bill (S1673).

Foster care is not the answer. There are not enough quality foster homes available to care for those who need foster care now. How can anyone imagine that such care could be found for additional hundreds from facilities such as Magnolia---- and these with very special needs as I have emphasized? This is being totally unrealistic. (Of course, Hewitt's age, too, would preclude him from this arrangement.)

Finally, small group homes are not the answer for the same simple reasons. To properly staff such facilities and meet the needs of these very special citizens would be virtually impossible. While some could perhaps survive and even prosper in a less structured, less supervised environment, many such as Hewitt could not. Efforts have been made at Magnolia to place Hewitt in specially selected off campus job situations, but each time he became nervous, hostile, and quite unhappy. It was concluded after several such efforts that he could not do this and needed the security of an on campus program. Also, who would constantly supervise the personnel of small group homes as the director, administrator, and board are able to do at a facility such as Magnolia? It takes a special kind of people to work with the mentally and emotionally handicapped. Who would make sure there were no abuses?

On behalf of my mother and myself, we earnestly plead with you to look into this matter. Do not let this bill slip through without a fair and proper hearing. Our lives and the lives of many of our most helpless and defenseless citizens are at stake here.

Sincerely,

Karen A. Trahan

Karen A. Trahan

April 9, 1988

Committee on Finance
United States Senate
205 Dirksen Building
Washington, D.C. 20510

Re: Medicaid Home and Community
Quality Service Act of 1987
S1673

Gentlemen:

Since I have a mentally handicapped daughter attending Magnolia School established in 1935 for the child who needs special methods of training and instruction, I am deeply concerned with the bill initiated by Senator Chafee of Rhode Island on Thursday, September 10th, S1673.

This business of "Mainstreaming" all persons with mental retardation is a disaster. All persons cannot be normalized, sad as it is. Just ask any parent of a retarded child. "Over Fifteen Bed" facilities are a vital and a necessary option for families with members who are severely and profoundly retarded.

At Magnolia School, Jefferson, Louisiana, there are nine cottages - kinda like the college campus where I attended the College of Pacific in Stockton, California. There is a Nursing Staff available at all times with arrangements at the famous Ochsner Hospital two miles from Magnolia School. The children are provided with educational opportunities, physical education activities such as swimming, bowling, horseback riding at City Park Stable where owners of horses lend their sadles, helmets and horses, games, sports, church, dances - you name it and it is there. Those who are able to work in the community are also provided with that opportunity. There are one hundred eleven residents and nineteen day students attend this ICFMR Facility.

As a parent and a concerned advocate for all handicapped individuals, I am asking that you help defeat this very controversial legislation as it now stands. I would strongly urge that S1673 be amended in such a manner as to accommodate persons with mental retardation who can only be served by larger facilities with complete in-house twenty-four supervision, including medical services.

There is nothing wrong with the bill if only the funds for larger facilities would not be capped and the parents continue to have a primary and not secondary role in decisions as to whether a particular resident should be transferred to a Group Home. Quality, not size, should be the criteria for all facilities. So long as facilities educate their residents, give them good care and prepare them for more independent living, size should not be a factor. Federal policy should not "rob Peter to pay Paul". The Chafee bill takes money from residents in larger facilities and gives it to those who live in their own homes or in Group Homes. Find the money some where else - they should be helped also but not at the expense of the larger facilities.

In no event should this bill be passed without a full hearing at which time time concerns of the parents of severely retarded children be fully aired.

Sincerely

Jessy Wolfe

Mrs Frederick J. Wolfe Jr
2426 Joseph Street
New Orleans, Louisiana 70115

TESTIMONY FOR SUBMISSION IN WRITTEN RECORD FOR
HEARINGS ON S. 1673
THE MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT

Submitted by

THOMAS D. WATKINS, JR.
Michigan Department of Mental Health

The Michigan Department of Mental Health is pleased to have the opportunity to submit testimony in support of S. 1673, the Medicaid Home and Community Quality Services Act. This legislation parallels the stated policy and program direction of the State of Michigan concerning provision of services to developmentally disabled individuals. Michigan strongly supports community-based services for persons with developmental disabilities. We have been committed to an aggressive community placement program and have developed a community placement system based on in-home support services, foster family or adoptive family placement, and small group homes. To maintain ICF/MR reimbursement a significant portion of our system of six to eight bed group homes has been designed to meet the requirements of the ICF/MR program. However, since the ICF/MR requirements were developed for large institutional settings, they are not really compatible with small group home settings.

Michigan would welcome a more flexible and more rational approach to services which the "Medicaid Home and Quality Services Act of 1987" would provide. We have tried to achieve such flexibility through development of various Medicaid optional services and through participation in waiver programs. The Medicaid waiver program does not assure continuity of coverages, requiring renewal every three years. Also the application and reporting requirements consume much staff time and expertise that could otherwise be devoted to improvements in program quality. Permanent restructuring of the Medicaid program to allow federal and state dollars to be combined in support of less restrictive and more appropriate care would be a very desirable alternative to the current fragmented programs.

Michigan does have a concern with the definition of case management which is contained in the current legislation. This requirement that case management be provided by an entity that does not provide other direct services is not compatible with Michigan's current community-based mental health system. Our system allows that case management be established as a separate function, reported directly to the administrator of the responsible mental health agency. However these services and other direct services can be carried out under the auspices of the same public agency. This is an arrangement which we believe to be cost-effective and one which gives good assurances of appropriate services delivery. We encourage consideration of modification to the current bill structure which would allow case management and other direct services to be provided, under a HCFA approved plan, by public service provider agencies.

Michigan strongly supports the bill's emphasis on helping people achieve their maximum independence and ability to fully participate in the community. We wholeheartedly support the philosophy and vision of the proposed legislation, and hope that our concerns will be considered as the bill moves through the legislative process.

STATEMENT SUBMITTED TO THE UNITED STATES SENATE COMMITTEE ON FINANCE REGARDING THE MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT OF 1987 (SENATE BILL 1673)

BY

SANDRA S. GARDEBRING, COMMISSIONER
DEPARTMENT OF HUMAN SERVICES
STATE OF MINNESOTA

I. INTRODUCTION

The State of Minnesota has historically provided extensive services for children and adults with severe disabilities. In addition to traditional long-term care services, the State has developed services in less restrictive settings such as Semi-Independent Living Services for adults with developmental disabilities, a Family Subsidy Program for children with developmental disabilities, alternative care grants for persons who are elderly, and a variety of home and community-based waivered services. The Medicaid Home and Community Quality Services Act, S.1673, embodies many values which are consistent with Minnesota's efforts to provide persons with severe disabilities more normalized living environments, individualized services, and the opportunity to improve their capacity for independence and personal competency. S.1673 supports, and does not supplant, the natural home — a value strongly reinforced by many of Minnesota's policies.

Minnesota was among the first states to use Medicaid funds to serve people with mental retardation or related conditions. We were one of the first states in the nation to develop Intermediate Care Facilities for the Mentally Retarded (ICFs/MR) as part of our State Plan to create community residential service alternatives. Use of Medicaid funding has enabled our state to reduce the population of persons with mental retardation who are in state institutions (Regional Treatment Centers) from over 6,000 in the 1960's to less than 1,600 today.

Based on our experience, we have been able to draw some important conclusions regarding the merits of various methods of service delivery. For example, we have learned that the extensive use of ICFs/MR leads to service costs that are high. In 1987, the costs for Minnesota of the ICFs/MR programs alone was approximately $230 million. However, a number of individuals who are eligible for service in ICFs/MR can be served equally well using less costly alternatives such as home and community-based services under the Medicaid Waiver program.

Minnesota has found it possible to move many individuals from our state and private ICFs/MR, to more independent settings under our Home and Community-Based Services Waiver and to demonstrate both an increase in service appropriateness and cost reduction. People were often placed into our large state institutions from their family homes and can be returned directly to their homes or home like settings if sufficient support services are made available to their families or residential staff. For example, 60 of the 209 children and adults moved from our regional ICF/MR treatment centers last year have moved directly home or into home-like settings under our Waiver. We continue to identify individuals for whom such a move is possible. A January, 1988 analysis of client needs in our regional treatment centers indicates that at least 259 of the people still in these ICF/MR settings could be served in home and community-based services. The number of persons residing in our community ICFs/MR who could move to home and community-based services is much larger.

Minnesota's model Home and Community-Based Waiver for medically fragile/technology assisted individuals has repeatedly demonstrated that the most medically fragile people can be cared for in their own communities rather than in an intensive care unit of a hospital. Not only can they be cared for in their own homes, but their physical condition improves and they are able to do things that their physicians believed to be impossible.

For example, Patrick is a child who is ventilator-dependent. He spent the first three and a half years of his life in an Intensive Care Unit of a hospital. He would still be there today if not for the Waiver. Under the Waiver, he can live at home with his mother and attend school with his peers. His mother receives the nursing support she needs to manage his care at home and at school.

Stories similar to Patrick's have been repeated throughout the state. Fortuntely, there are not a large number of similarily technology dependent individuals. However, modern technology has saved the lives of many premature infants and severe accident victims. If we are willing to save these individuals, we must also be willing to support them and their families with the services that they need and allow them to live as normal a life as possible.

Despite the demonstrated success of community placements, fiscal disincentives to "non institutional" settings have existed since the inception of Title XIX funding and continue to exist today. Even the Home and Community-Based Services Waivers, which are an excellent alternative, do not allow movement of enough individuals to community services. Waivers are often viewed by parents and providers as temporary, due to Health Care Finance Agency's (HFCA) authority to approve, deny, terminate and/or renew the State's Waivers. States are required to demonstrate the services will be cost neutral as part of a complicated formula which is difficult to develop and which must be approved by HCFA of the Department of Health and Human Services. However, more traditional "institutional" services are included as a portion of a state's Medicaid Plan. Revisions to each state's Medicaid Plan are much less complicated that applications for waivers and are more within the control of each state. The stability of state plan services and ease of administration favor services that can be developed and supported using that mechanism. Thus, the system still seems to favor medical, institution-based services rather than home and community-based services. We believe the provisions of S.1673 are essential to further movement toward home and community-based services and therefore strongly support the bill. Rather than comment on each provision we would like to highlight a few provisions we feel are key to the provision of services in Minnesota.

II. SPECIFIC PROVISIONS

A. Provision of services based on need. We strongly support the provisions of S.1673 which enable us to provide service based on need. Several years ago, the parents of a ten year old child called Minnesota's Department of Human Services to inquire about facilities which could serve their daughter. They wanted to keep her at home, but were told by the county case manager that money was not available and that the only environment available where services could be funded and provided was a regional treatment center (large ICF/MR). After visiting the regional treatment center the parents decided instead to keep their daughter at home. Shortly thereafter, the daughter ran away from home, was sexually assaulted, and was subsequently placed in a regional treatment center. After two years there, Minnesota was able to use the Home and Community-Based Services Waiver to develop a foster home for the adolescent. She continues to live in that home today, succcessfully attending school, frequently visiting her parents at home, and vacationing with her parents. Obviously, this child experienced two years of unnecessary institutionalization and removal from her community. Making family support services available, based on need rather than on an arbitrary formula which is linked to existing service costs, would often prevent unnecessary institutional placements and unnecessary expenditures required for these placements. S.1673 would enable states to determine children under 18, living at home, eligible for services based on the child's income and resources regardless of the income of other family members in the same way we determine elegibility for services n our large ICFs/MR. This would eliminate an unintended bias toward ICF/MR placement where parents can place their children into our large ICFs/MR and, except for a limited fee schedule, these parents are relieved totally of the costs of their child's care.

B. Inclusion of case management in the array State Plan services. Minnesota and other states have been using case mangement services to provide for the individual service planning and oversite necessary to ensure quality services. Consumers are often overwhelmed by the complexity of program and eligibility requirements. They may have trouble accessing services and selecting the most appropriate services. This often results in a delivery system which does not target resources in a way that assures people receive what they actually need, no more and no less. S.1673 would include case management and an Individual Habilitation Plan as part of the required array of services, a position which Minnesota supports.

C. Provision of service options for states. The Medicaid Home and Community Quality Services Act allows states to have more flexibility to choose from the available service options those services which the state determines to be necessary and appropriate. If there is one generalization that can be made about people with disabilities, it is that they are not a homogeneous group about whom many generalizations apply. Similarly, each state has a unique set of circumstances within which it must operate. Establishing a core set of required services, but allowing flexibility in selecting other optional services, reflects an appreciation for differences in state needs and resource availability.

D. Elimination of reapplication process for waivers. Current HCFA regulations require states to use an arbitary "cost effectiveness" cap and reapply at the end of each Waiver period. This policy has the effect of forcing state agencies to devote sizable resources to the process of preparing applications, computing formulas, and repeatedly defending the legitimacy of their requests. S.1673 eliminates the "cost effectiveness" computing formula cap and the need to apply and re-apply for waivers to provide services.

E. Inclusion of improved quality assurance mechanisms. As individuals move from institutional settings into small dispersed living arrangements, we have been impressed with how they benefit from these new living situations. Their parents, advocates, and interested citizens often share success stories with us. Neighbors, church members, school mates, and other community residents — bus drivers, business people, scouts — provide an informal network of friends who safeguard the quality of life for people with disabilities. However, there is a need for formal quality assurance mechanisms to oversee a system serving such a vulnerable group of individuals. We are supportive of the requirement contained in S.1673 for such a system.

F. Simplification of administrative processes and inclusion of administrative costs. Administratively, S.1673 provides more stable funding and simplifies the administration of home and community services. It also includes federal financial participation (FFP) for the administrative activities required by the legislation.

III. SUMMARY

Jason, who is five years old, lives in rural Minnesota. Two years ago Jason fell into a swimming pool and wasn't discovered for 10 - 15 minutes. He has all the medical labels that would classify him as among the most handicapped of children living in any institution. He no longer walks, can't talk, may or may not be able to see, and clearly does not respond to his world the way a child his age normally would. His parents have been struggling to get through the anguish of what's happened, to find the strength to support each other and keep the family intact, while at the same time trying to obtain services for their son. Luckily, they were able to get home and community-based services from Minnesota's waiver to support their efforts as a family. Unfortunately, other children and their families have not been so lucky. They may live in a state which does not have an approved home and community-based waiver services waiver or where the services under the program are so severely limited that their parents are left with no choice but to place the child out of their home.

Federal and state legislation have consistently moved in the direction of community services, however, funding has not always followed. The value of providing support for families has been expressed in concept, but it has not always been backed up by the allocation of resources to support the concept.

Why will we pay thousands for institutional care, but not hundreds for home care support?

The Home and Community Quality Services Act is not, as some have suggested, an attack on traditional models. It does not force states to close existing institutions. But it does create a holding pattern for the costs of such care to allow us to re-direct funding in a manner consistent with our stated policy of supporting people in their own homes and community. This legislation allows individuals and their families decide where they will receive needed services.

All of the major organizations representing citizens with developmental disabilities are in favor of passage of this bill. The involvement of so many key stakeholders presents a high degree of willingness to work together in the difficult implementation phase which accompanies any significant piece of legislation. This support will be particularly helpful in the five year planning process.

There are, of course, implementation questions that need to be addressed regarding this bill. The information tracking system and quality assurance provisions are both important, but sufficient time must be provided to allow states to come into compliance. HCFA's sanction authority will need to be established by Congress. In addition, the public hearings required to develop a plan will have some costs associated with them and we will need to consider how to deal with that issue.

Nevertheless, this legislation addresses issues in a humane way and targets money were it is really needed; to establish home and community-based services individuals and their families. Minnesota strongly advocates for passage of S.1673. It will help us to answer the questions parents and family members have been asking for years: "What happens if we are unable to care for our child or relative?" "Where does my child go after special education?" "Why do I have to be impoverished in order to receive supportive services?" This bill gives us freedom to allow for more normal living, working, and leisure time alternatives for persons with disabilities. Hopefully it will do so in a way that is not prescriptive or simplistic in assuming that all people require the same things.

To Laura Wilcox

Iam the father of Dennis John Martinez Jr. a special handicapped child born to me on January 20 1976 and has been living to presently since they told my late wife Gloria and I that he would not live within 6 months. Hewas given last rites at 3 weeks old due to his illness of Spinal Menigitis in the brain area. We kept him at home after he came out of hospital in March of 1976 til he was commited to Augustana Center on May of 1977. Ive been proud of every breath he takes , for he made a better person of me to be involed with many civic and political organizations locally and city wide . I promised my late and dying wife Gloria I would do every in my power to take care of Dennis Jr. and his special handicapped friends on August of 1982. Idid so by rasing monies for the Augustana Parent Group since 1977 til the present, Ive been the top fundraiser thanks to the wonderful support of the people of South Chicago area Iworked and socialized with the parents of special handicapped persons at monthly meetings to fundraisers to volunteering on tag days to the Special Olympics on May of every year at Soldier,s Field in Chicago ILL. I am always involed with parents hoping we would form a very strong support group for each other by being consistently involed with all the specially handicapped persons at the Augustana Center. I became President of the Augustana Parent Group in 1984 that is when we first heard of this federal bill which they changed 4 times since then . We discussed and had lawyers interpetthis billfor us and were shocked to find out what this bill would do to all specially handicapped centers in the United States. Presently Iam The Board Member of the Augustana Parent Group since 1980 which represents 150 specially handicapped children and adults who most are profoundly mentally and physically disabled I also represent 130 parents that have their children and adults at the center presently .. We the Augustana Parent Group have been opposed to this federal senate bill since 1984 til the presentdue to the drastic living extreme conditions of all large centers being phased out in 10 years and being replaced by all small centers in the United States . This federal bill came so suddenly becauce we were not informed or given information from the federal governmenttil it was almost to late to put in our recomendations on this federal bill.We the active parents have been angry with this bill and all the 130 parents have given us approval to opposed this bill in its present form . We could have worked with you by telling you that there was not enough doctors, therapists, nurses, and workers to make this bill workfor the benefit of all the special handicapped children in the United States. We parents need to be treated like intelligent human beings to be able to functionwith a balance of humanes and intelligence,not by pity and telling us for our own good because we are to emotional.So to prove our intelligence and humaness we want to be part of the government decision making policies especially handicapped issues.We the parents of the Augustana Parent Group have been making recomendations since 1984 til presently .to Senator John Chaffee was given a copy in April of 1986 when he came to Chicago to hear testimony of parentswhich none were from Augustana or Misrecordia in Chicago area..

mississippi friends est. 1985

PO BOx 427
Meridian, Ms. 39302
April 11, 1988

Committee on Finance
United States Senate
205 Dirksen Building
Washington, D. C. 20510

Gentlemen:

As concerned citizens of the state of Mississippi we would like to express our opposition to Senate Bill NO. 1673, Medicaid HOme and Community Quality Services Act of 1987.

While we realize that it is important for our mentally retarded citizens to make every effort to become independent, it is important to remember that many individuals in this category could never reach this goal. We feel that it is much more realistic to allow our severely disabled to be able to live in the least restrictive environment possible, but with all the necessary services they require. Small rural communites such as we have in Mississippi would not be able to provide the special needs and professional people for our severely and profoundly retarded. THe costs for such services would be prohibitive, even if it was possible to find all the necessary personnel to work at such places.

Additionally, small communities still are not ready to accept the severely handicapped into their communities. We agree it would be an ideal situation, but the attitude of the general public is still very slow to accept the mentally retarded into the community and work place.

This is only a brief summary of some of the problems with this bill. We ask that you take great care in making your decisions on this bill since this effects the lives of many mentally retarded individuals and their families.

Very truly yours,

Jacquelyn Crawford, President
STate Assn. of Parents, Guardians,
and Friends of the Mentally Retarded

the state association of parents, friends, and guardians of the mentally retarded

Statement of
The National Association of Rehabilitation Facilities

on

The Medicaid Home and Community Quality Services Act of 1987
S.1673

The Medicaid Home and Community Quality Services Act of 1987, S. 1673, could be the most important legislation Congress could pass during the 1980's affecting persons with severe disabilities. The National Association of Rehabilitation Facilities believes that the bill offers a reasonable alternative to institutional care and offers persons with the most severe disabilities the opportunity to live as independently as possible. The National Association of Rehabilitation Facilities (NARF) represents over 700 rehabilitation facilities around the country providing a wide range of vocational and medical rehabilitation services to persons with severe disabilities. At it's October, 1987 meeting the NARF Board of Directors voted to endorse the concept of The Medicaid Home and Community Quality Services Act of 1987 . This position was renewed at the most recent Board meeting in January, 1988.

The bill offers both a range of living arrangements that will best meet the needs of each individual, and access to services which will allow them to grow to their greatest potential. It has long been recognized by community service providers that deinstitutionalization is meaningless if there are not the appropriate services available in the community, or if those services are not adequately funded to provide quality services to all who could benefit, regardless of the severity of their handicapping condition.

It is especially important that the vocational services to be funded under the bill allow a variety of employment alternatives, thus providing the services and employment setting which best meets the needs of each individual with a disability. Likewise, the living arrangements provided through Federal funding for persons with severe disabilities should reflect the needs of the individual while ensuring a community-based setting.

The persons with disabilities who will benefit from the Medicaid Home and Community Quality Services Act can benefit greatly from the services that will be both mandated and discretionary. These services include:

- case management
- individual and family support
- specialized vocational services
  - pre-vocational
  - supported employment
  - other services leading to integrated employment
- protective intervention
- habilitation services
- case coordination
- educationally related services
- occupational therapy
- intervention therapy
- diagnostic and assessment services

- personal assistance and attendant care
- homemaker and chore services
- respite care
- specialized training for families and care givers
- special transportation
- personal guidance
- preventative services

These services are available now, or can be quickly started, from community-based rehabilitation facilities. The problem faced by these facilities and the persons with disabilities who could benefit from these services is a lack of funding. In many cases, the funding is not there at all. Some persons are referred to facilities with no funding for the services they need. Either they don't meet the eligibility criteria for a particular program or the program is not sufficiently funded to provide services to all the persons who are eligible. The multitude of programs that may provide funding for services can also be problematic. Often a person gets shuffled from one program to another as each program tries to find someone else to accept responsibility for the client.

Another compounding problem is that persons who are currently institutionalized can usually only receive services from that institution. Many institutions, especially those larger state run programs, are often geographically isolated from the potential sources of community-based services.

S.1673 addresses both of these issues. Utilization of Medicaid funding would offer both the state and the service providers much more certainty and predictability of funding than is currently the case. For many severely disabled persons, they will, for the first time, have a right to services rather than just eligibility for services they might or might not actually receive.

The current system encourages little more than basic maintenance. The Medicaid Home and Community Quality Services Act not only encourages, but mandates, services which will enhance the quality of life for persons with severe disabilities. In the area of employment related services the bill offers for the first time access to a funding source for the long term follow-along services for supported employment that can truly be ongoing without time limitation. Follow along services might include checking with the disabled worker on a periodic basis, giving additional job training or adjustment assistance as needed, and helping new supervisors or other employees at the supported job site make needed adustments. While these follow along services are relatively inexpensive, the services need a funding source that will not be continually subject to change.

The fact that the funding is tied to the individual makes it ideal for the follow along part of supported employment. Surveys by the National Association of Rehabilitation Facilities and others have clearly shown that the lack of an identified sources for long term follow along services is the major impediment to greater utilization of supported employment.

The bill also encourages the type of residential facilities most likely to be sponsored or managed by community based rehabilitation facilities. A large percentage of the persons served and employed by rehabilitation facilities live in group homes. Lack of residential programs is often a problem to getting mentally impaired or developmentally disabled persons into rehabilitation programs. This bill would provide the incentive to the states to develop and fund these community based residential programs.

While NARF supports the concept of the bill, there are areas where NARF feels the bill could be improved. Not all facilities would benefit from the bill. Some facilities do operate ICFs/MR that would possibly see reduced funding even though the medium-sized programs (usually 20-30 beds) were built as alternatives to larger state institutions. The bill should recognize the unique role these facilities play and insure that they do not suffer.

The bill favors supported employment as the method of providing employment and employment related services to persons to be served. Rehabilitation facilities firmly believe that supported employment is an important employment option that should be made available ,where appropriate, to persons with severe disabilities. Sheltered employment should also be allowed as an option under the mandatory services in the bill. Employment services, like residential services, under the bill should be based on the needs of the individual, not on any preconceived notions of what is best for the individual. Sheltered employment , (i.e., employment developed specifically for disabled persons often in special facilities) may be the most appropriate placement for persons with severe disabilities. This is especially true where the disabled person has severe behavior problems or where the employment opportunities are limited in the community. In many cases sheltered employment offers wages, benefits and working conditions which are comparable to or better than those available outside the facility. Special programs such as the Javits-Wagner-O'Day program provide Federal contracts to employ disabled workers in performing work for the Federal government. The bill should specifically recognize sheltered employment as one of several legitimate employment outcomes under the bill.

While the bill clearly promotes providing services at the community level, it does not go far enough to make sure that existing community resources are used. There are already thousands of community based rehabilitation facilities across the country that can provide the services called for in the bill. The costs to the states and the Federal government will be substantially increased if the states try to create a new service delivery system for the services called for in the bill. The bill should contain language requiring utilization of existing resources where possible and where such facilities meet reasonable accreditation standards.

While NARF would like to see the above mentioned changes, we think that S.1673 should be favorably reported by the Senate Finance Committee and sent to the floor even without the suggested changes. The bill and the concept behind it have been under consideration for more than four years. It is time to take action on the bill and on the concept.

NCIL

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Chicago, Illinois 60607
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Representing
all disabilities

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Vancouver, Washington

April 8, 1988

Laura

The Honorable Senator Lloyd Bentsen
Chairman Finance Committee
United States Senate
Dirkson Office Building, Room 205
Washington, D.C. 20510-4301

Dear Senator Bentsen,

As Chairperson of the Long Term Health Committee of the National Council on Independent Living (NCIL), I wish to communicate the position of the Council with regards to the Medicaid Home and Community Quality Services Act of 1987 (Medicaid Reform Act).

The purpose of NCIL is to promote the development, improvement and expansion of viable, community-based, consumer-controlled independent living centers and programs which facilitate the integration of people with disabilities into all aspects of society. The improvement of the quality of life choices for all people with disabilities will be achieved through advocacy efforts nationally.

The disabled population served by independent living centers include persons who are developmentally disabled. As service providers to this population, we are very aware of the problems that many of them face as they try to remain in their homes without adequate, appropriate and affordable services. Medicaid funding for home services could lift the specter of institutionalization from many of these people.

However, NCIL is very concerned about certain portions of this Act and would like to recommend amendments. First, we would strongly urge the incremental increase of eligibility over the age of 22 years to be five year increments instead of one year increments. Secondly, State Independent Living Councils now comprise an important part of each state's plan under Title VII of the Rehabilitation Act. The Councils contain consumers' input and should be an equal player with DD Councils and Protection and Advocacy Agencies to review the Medicaid Plan. Third, we recommend that the Bureau of Developmental Disabilities be changed to the

Ltr Sen L Bentsen
4/08/88
Page 2 of 2

Bureau of Disabilities. Lastly, NCIL feels very strongly that persons with disabilities, along with parents and professionals need to be included in the monitoring of services. Without including persons that are consumers, we are denying the right for input of individuals who are or potentially can be the recipient of these services.

NCIL requested to appear at the March 22nd hearing in Washington, D.C. but was denied this opportunity. We would ask that this written testimony be put on file to record our concerns. We would hope to be included in future public hearings in order to voice the opinion of consumers with disabilities.

We are open to and encourage any further communication on these matters. Your time and concern are appreciated.

Erica C Jones
Erica C. Jones
Chairperson, NCIL
Long Term Health Committee

ECJ:la

cc: Senator George Mitchell
Chairman of Sub Committee on Health

TESTIMONY

by

Arthur Y. Webb
Commissioner

New York State Office of Mental Retardation
and Developmental Disabilities

March 22, 1988

Introduction

As the Commissioner of the New York State Office of Mental Retardation and Developmental Disabilities, I wish to commend the members of the Senate Finance Subcommittee on Health for their interest in measures that encourage states to expand and improve home and community-based services for persons with disabilities. Thank you for this opportunity to comment on S.1673, the "Medicaid Home and Community Quality Services Act of 1987."

I. New York's Position

I would like to present, in this testimony, background on New York's system of care for persons with developmental disabilities and our experiences with the Medicaid program. My position on the "Medicaid Home and Community Quality Services Act" can best be understood in this context. However, let me make my position clear at the outset.

I believe that reform of the Medicaid financing system for services to persons with developmental disabilities is essential to the stability and needed expansion of states' developmental disabilities systems. Nonetheless, the "Medicaid Home and Community Quality Services Act" is not the answer and enactment of this legislation would not be in New York's or in other states' long-term interests. My position on this is a departure from that taken by the National Association of State Mental Retardation Program Directors as represented by the testimony you received from Mr. Ron Welch, president of the Association. I believe that many of my colleagues have mistakenly embraced a hoped for federal panacea for many of the problems that can only be solved by hard work and political commitment in state governments and bureaucracies.

This proposed legislation is problematic from two perspectives: First, the bill is conceived from a mistaken assumption that there is an inherent institutional bias in the ICF/MR program. I do not believe that this is so and a fair analysis of all the available data would bear me out. New York's experience shows that a community-based system of care can be accomplished using the ICF/MR program. Nationally, the data presented by Charles

Lakin[1] shows that between 1982 and 1986 small community-based ICF/MRs increased by one hundred fifteen percent while institutional ICF/MR populations decreased by over six percent. Second, the bill is argued from a perspective that denies the reality of the states' commitment to accomplishing community-based systems of care for persons with developmental disabilities. To be sure, there are legitimate and important public policy discussions unfolding about the pace and nature of deinstitutionalization, yet the central commitment of state governments to community-based service systems is not questioned in most areas of the country. David Braddock's study of national public spending in this field bears out the real investment in community programs. He notes "a dramatic and continuous climb in nationwide community services fiscal effort."[2]

We need to reform the Medicaid system of funding community-based services to this population, but we do not need fiscal coercion from the federal government to divest funds from larger facilities in order to get states to invest in community-based care. We must recall that the community and client rights movements on behalf of MR/DD people were based on an outrage at the poor quality of institutions. We have corrected that wrong largely with the help of the Medicaid program. We cannot take two steps back to go one step forward.

II. Overview of New York's System of Care

The New York experience reflects our commitment to improved quality in all settings and a dramatic expansion in community care. New York State has the largest and probably the most well developed system of community and center-based care in the nation for persons with developmental disabilities. The New York State services' system accounts for approximately 20 percent of all Medicaid funds expended in the nation for mental retardation and developmental disability services. The Office of Mental Retardation and Developmental Disabilities oversees a service system for some 28,400 persons in residential programs and 38,500 persons in day program settings.

Since 1975, New York has delivered on its strong commitment to deinstitutionalize large institutions. This commitment is a state initiative. Our developmental centers housed over 20,000 persons in 1975. Today, there are fewer than 9,500 persons remaining in developmental centers, while over 18,000 individuals receive residential services in community-based programs. An additional 16,000 families receive support services for disabled family members living at home. Governor Cuomo announced in January of 1987 that we would close seven of our developmental centers by 1991. We closed the Staten Island Developmental Center--more familiarly known as "Willowbrook"--during 1987, and our plans to close the other six institutions are well underway.

The growth of our community-based system has occurred in large part as a result of federal participation through the Medicaid program. However, the restrictions imposed on the use of Medicaid funds and the uncertainty that has resulted from the Health Care Financing Administration's (HCFA) management of this basic program presents a real obstacle to New York's fulfillment of its goal of an expanded and cost-effective community services system. It is not the Medicaid program nor the ICF/MR that prevents community care; in fact, the ICF/MR program is as much a community program as it is an institutional program--if not more. The issues have been clouded and entangled in sophistic and emotionally charged rhetoric. The issues are not institution versus community nor ICF/MR versus community living facilities. The issues are much simpler: What public policy enables states to maintain and increase quality of care in all settings? And what reforms are necessary to enable states to stimulate expansion of community care systems with the use of Medicaid funds? Both issues can be resolved without emasculating the ICF/MR program or destroying the hard-won quality now found in larger centers.

Senator Chafee's bill is a well formed answer to the wrong question.

III. New York State's System of Care and the Role of Medicaid in Financing the Continuum

First, let me put those statements in the context of an overview of the current MR/DD system in New York State and the direction we foresee in terms of program expansion. In the early 1970s, great impetus was created to redirect the system away from institutional service provision to community-based program alternatives. Pressure to do so was created as a result of civil rights federal court cases, and the initiative was reinforced by major federal statutes which articulated these rights and created new service modalities to better respond to the needs of handicapped citizens. While the initiative was there, sufficient federal funds were not available to support implementation. Only the Medicaid program with its categoric entitlement for the permanently handicapped, provided the potential for federal financial support to any meaningful degree.

New York State used this state-administered program to further its efforts to return to the community people who had been institutionalized, and to upgrade the quality of services for those individuals who remained in institutional settings. Today, more than 7,000 individuals (many of whom are former institution residents) live in community-based intermediate care facilities. During FY 1987-88, OMRDD opened 1,945 new community residential beds, 682 of which were ICF/MRs. The average bed size of these new community-based homes is ten. In New York City, 393 community residential beds were developed. This is more than in any other year in our history. The average bed capacity of all new residential beds, including family care homes is five; more than half of these new programs serve three or less persons with developmental disabilities. No significant difference in bed size exists between the ICF/MR program and community residences, a non-Medicaid program. Clearly, this illustrates that a community-based system, comprised of smaller-sized residential beds, can be accomplished by using the ICF/MR program.

Medicaid payments currently support services to approximately 70 percent of the developmentally disabled persons receiving residential services in New York State. We have also elected to include Medicaid-funded personal care services as a component of the family care program and have built a similar component into the community residence program. The availability of Medicaid has furthered the development of the day service continuum; OMRDD offers day treatment, which is Medicaid reimbursable, to approximately 18,000 substantially disabled individuals who comprise more than 45 percent of all day service recipients. Without a doubt, the expansion of developmental disabilities services in New York State is directly attributable to the increase in federal financial participation through Medicaid. If this were unavailable, it is conceivable that the system of services would not have moved as dramatically as it has to community-based care.

Let me just emphasize this: The growth of our community programs is directly due to the existing Medicaid program. This was done without a home and community care waiver. In summary, the Medicaid program has been used in New York State to move the service delivery system away from institutions and toward the community.

While we, as an agency, are pleased by our accomplishments, there remains a major service development task ahead of us. Our efforts to reduce the developmental center population and to close institutions will continue. At the same time, the energy and administrative commitment that has been devoted to deinstitutionalization must be extended so that our system can also expand its capacity to serve developmentally disabled persons who have remained at home with their families. This group includes young adults who are being graduated from the special education system and who need vocational training programs. It includes older mentally retarded persons with aging parents who can no longer provide consistent long-term care within the home. It also includes infants and young children who may benefit from early intervention services that lessen the long-range effects of developmental disabilities. In all cases, it is important for us to provide support services to the families of our clients so that their abilities to continue offering informal care is sustained.

As evidence of OMRDD's commitment to this unserved population, we plan, by 1991, to serve 6,600 more people in the community residential continuum and to double the number of persons who participate in day programs, which necessitates the development of habilitation and vocational training services for an additional 14,500 developmentally disabled adults.

It is because of New York's experience that I depart from my colleagues who argue for Medicaid reform because of a supposed institutional bias in the present system. To be sure, the statistics bear out that the ICF/MR program largely funds institutional beds. This is due to the historic fact that states have used this funding source initially to upgrade the quality of care in their existing institutional settings. In New York we did not stop there. Rather, we aggressively pursued the ICF/MR program to develop a community-based system of care. The New York experience shows that states with political will and commitment can effectively use the ICF/MR progam to meet their obligation to serve people in community settings.

There may be problems with the ICF/MR program, but institutional bias is not one of them. Clearly, the ICF/MR program is expensive, with many of the expenses driven by regulatory requirements unrelated to client needs, client safety or quality of life. Also, the ICF/MR program requires that the full complement of services be given to each eligible client, even when a client may best benefit from one or two of the ICF/MR services.

IV. Specifically, What Problems Does S.1673 Have?

The "Medicaid Home and Community Quality Services Act" contains provisions that could certainly enhance the lives of persons with developmental disabilities. There is much to commend in this legislation that would assist states to expand and improve upon home and community-based services.

Nonetheless, I can not support the legislation because certain of its provisions would have a negative effect on New York State, other states, and especially, on the clients it intends to serve. Because the legislation is grounded in false assumptions about the dynamics that allow state governments to pursue successfully expanded community-based care, it will, in the long run, harm state systems. Furthermore, some of the fundamental problems with Medicaid-funded systems of care for persons with developmental disabilities will remain unaddressed.

First, Section 4 of the bill amends Section 1903 of the Social Security Act. This amendment establishes a freeze on the maximum federal financial participation payable to a state through Medicaid for people with developmental disabilities living in ICF/MR programs with 16 or more beds. New York State would be capped at the amount received during the fiscal year in which the bill becomes law. This freeze--which is not indexed for an individual state to accommodate union negotiations, fixed-cost trends, most inflation, necessary capital improvements, or even the cost of deinstitutionalization--would constitute a real cut by the federal government. There are costs that are incurred as states seek to downsize and close their institutions. The bill, by not providing for the federal government to share in these costs, creates a real disincentive to states to pursue institutional closure.

Second, the bill prohibits routine funding for room and board costs for small community residential programs. Currently, Medicaid pays for room, board, and capital development associated with the establishment and operation of all ICF/MR programs including small community-based programs. The bill assumes that Supplemental Security Income could pay for room and board and states would pay for capital construction and major renovations. However, our experience with our non-Medicaid community residence program is that Supplemental Security Income alone cannot cover room and board costs. Furthermore, states are more apt to meet growing need by expanding their service system for community programs if the up-front capital expenditures are shared with the federal government. This prohibition, thereby, would make program development more difficult. This provision of the bill would also remove reimbursement for a service that is now funded in the ICF/MR program.

Room and board are housing services for mentally retarded and developmentally disabled people that Medicaid recognizes as legitimate in the current ICF/MR program. The bill arbitrarily eliminates this important category of service for this population. This oversight is evidence of the legislation's misunderstanding of one of the important dynamics of the ICF/MR program as a vehicle for states to accomplish community-based systems of care. Here's a good example of the bill's inadequacy: Because the ICF/MR program reimburses capital, it currently contains one of the best incentives for community development. This very incentive would not exist if Senator Chafee's bill were to become law. In New York State, therefore, an ICF/MR, not a community and family living facility, would still be the strongest vehicle for community care expansion. I am left thinking of the signs on New York City's subways during W.W.II: "Was this trip really necessary . . . ."

However, if this bill were to go forward, I would advocate for certain modifications. The bill should be modified to include explicit language that would allow states to claim, as a reimbursable expense, capital costs associated with development, purchase, renovation, leasing and start-up of new community-based facilities that are not ICF/MRs. States should also be allowed to claim room, board, and meal service costs in excess of the SSI payment as a reimbursable expense. Medicaid reimbursement for costs associated with census reduction and closure of a large facility undertaken as part of a state implementation plan should also be provided. The current bill would create an incentive for a state to let quality decrease, thereby triggering an HCFA survey, which then could be addressed with a reimbursable closure plan.

V. If Not S.1673, Then What Would You Propose, Commissioner?

As the Commissioner of one of the largest long-term care service systems for persons with mental retardation and developmental disabilities, I have listened intently to the national public debates on long-term care Medicaid reform, and I believe that there is a need for a new direction in the national developmental disability policy area. We must be able to answer the real questions:

- How do we maintain quality in all settings?
- How do we stimulate community-based services?

Within the last few years, several progressive proposals, in addition to the "Medicaid Home and Community Quality Services Act of 1987," have been put forward that could answer these questions by reforming Medicaid. These proposals include:

- New York State's Office of Mental Retardation and Developmental Disabilities' Medicaid waiver proposal.
- The Omnibus Budget Reconciliation Act of 1987, Section 1915(d).

These proposals have sought to reconfigure the Medicaid system, although the means used to realize Medicaid reform are distinctly different for each. Certain aspects of these proposals can form the basis of a new direction in long-term care policy for the nation.

A. NYS/OMRDD Medicaid Waiver Proposal

A number of years ago, we came to the conclusion that some basic changes had to be effected in Medicaid for New York State to meet its long-term service goals--that is, to serve more people, to provide an effective array of quality services, and to develop a continuum of care for persons with developmental disabilities that was more affordable to the state and federal governments.

Based on our conclusion that dynamics in the current Medicaid-funded system of care would thwart our best efforts to achieve these service goals, we proposed a series of waivers to the federal Health Care Financing Administration (HCFA) under Section 1115 of the Social Security Act for a demonstration project. These waivers would assist New York State in reforming the Medicaid financed long-term care service delivery system for persons with mental retardation and developmental disabilities and make it more cost effective. With this demonstration project, New York State could continue its deinstitutionalization efforts, assure quality of care for all persons served in its system, and meet the legitimate growing demand for services to persons living in the community.

The proposed project would expand the basic service and eligibility entitlements contained in the Medicaid program for the MR/DD population. This system is currently oriented toward costly and highly regulated programs. Proposed changes would produce a service system that stimulates cost-efficiency and service appropriateness, provides regulatory standards that promote quality of care and individualized services, and ensures the capacity to provide services to a significantly greater number of needy and eligible clients at lower per capita cost. Through requested waivers, the existing Medicaid-supported, long-term care system would be transformed to shift costs from Medicaid programs to lower-cost Medicaid and non-Medicaid programs.

The requested waivers would allow Medicaid payments for additional home and community-based services, while expanding Medicaid eligibility to many substantially developmentally disabled persons who would otherwise not be deemed Medicaid eligible. Vocational services, case management, personal care, in-home care, supportive work, transition to work, clinical services, transportation, and respite/family care services, among others, would be covered under the demonstration project. Essentially, this would make available, as needed, any OMRDD authorized long-term care service to the expanded group of developmentally disabled persons. This proposal expands and emphasizes the community without eroding the successes of the current Medicaid program.

Cost-containment is also a product of this waiver demonstration proposal. The proposal includes economic modeling and forecasting that demonstrates the ability to contain the cost of total system growth to a level below that projected using current regulations, policy, and trends. New York can demonstrate significant cost savings through a demonstration project based on regulatory flexibility and a different formula for determining the federal/state partnership that cofinances long-term care services for this population. In brief, make a greater array of lower cost options available in the community and more disabled people will use them.

To date, OMRDD has submitted three waiver proposals to HCFA; none of these have been funded. HCFA has been reluctant to engage in research and study on this aspect of long-term care.

I am hopeful, however, that this kind of endeavor will help resolve persistent issues and allow us to achieve a stable, predictable and manageable system of care that can more adequately revolve around client and family needs.

B. OBRA 1987

A second progressive proposal that could potentially serve as an alternative method of financing long-term, community-based services for persons with developmental disabilities was adopted as part of the Omnibus Budget Reconciliation Act of 1987 (OBRA-87). This act created a new home and community-based waiver authority for the elderly by adopting Section 1915(d) of the Social Security Act. The waiver allows states to establish a cap on total federal financial participation for long-term care services, which include institutional, home and community-based services, home health, private duty nursing, and personal care services. This capped amount would be increased by an inflator which reflects the market basket indicator in long-term care costs. In exchange for the cap, states would have unlimited flexibility to provide a variety of service options to an increasingly larger number of persons. This kind of approach is so much better than that contained in S.1673. It creates incentives and awards for service, not penalties and disincentives.

It is my understanding that the House Subcommittee on Health and the Environment is considering developing similar waiver provisions for persons with developmental disabilities.

VI. Conclusion

Federal policy for disabled persons as reflected through various programs, funding, services, and regulations is fragmented, uncoordinated, and inconsistent. It is clear that a new direction is needed in the national developmental disability policy arena. The time has come to develop national policy for developmentally disabled persons that is coordinated in its organization, comprehensive in its design, and effective in its implementation. The states and the federal government must work together to forge a partnership that renews our shared commitment to developmentally disabled citizens.

As we look to define the basic tenets that will form the basis of a national policy direction capable of meeting the varying needs of all disabled persons within a fiscally constrained environment, we must not overlook the merits of these three long-term care reform proposals.

Certainly S.1673, the "Medicaid Home and Community Quality Services Act of 1987," contains provisions that could enhance the lives of persons with disabilities. However, the bill also contains features that would have a negative impact on New York State as well as other states. New York State's Medicaid waiver proposal and a Section 1915(d)-type waiver for persons with developmental disabilities could be helpful in building a more rational and equitable service system. I believe that there is room for discussion and compromise among these proposals.

Once again, I would like to commend the members of the Senate Finance Subcommittee on Health for their support and concern for this nation's citizens with developmental disabilities. Your continued assistance in expanding community-based service options and the quality of care provided to our developmentally disabled citizens is recognized by many constituencies in the State of New York.

Thank you for the opportunity to present testimony on this extremely important matter.

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[1] K. Charles Lakin, et. al., "Medicaid's Intermediate Care Facilities for the Mentally Retarded Program: An Update," Report No. 25 (Minneapolis: University of Minnesota, Department of Educational Psychology, November 1987).

[2] David Braddock, et. al., "National Study of Public Spending for Mental Retardation and Developmental Disabilities," American Journal of Mental Deficiency, Vol. 92, No. 2, 1987, pp. 121-133.

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Member
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LYLE STITT

March 31, 1988

Honorable George Mitchell
Chairman
Subcommittee on Health
Senate Committee on Finance
U.S. Senate
205 Dirksen Building
Washington, D. C. 20510

Dear ~~Senator Mitchell~~ George:

On behalf of the State of Wisconsin Department of Health and Social Services, we would appreciate the attached testimony on S. 1673, the Medicaid Home and Community Quality Services Act, being inserted into the hearing record on the subject pursuant to a March 22, 1988 hearing before your subcommittee.

We also appreciate the committee's taking into consideration the State Department's views on the legislation. I am certain that the Department Secretary, Timothy Cullen, and his staff would be pleased to discuss the matter with your staff.

Thank you for inserting the enclosed statement into the hearing record.

Respectfully,

David R. Obey
Member of Congress
7th District, Wisconsin

Attachment

cc: Timothy F. Cullen, Secretary, Department of Health and Social Services

STATEMENT FOR THE RECORD

BY

R. DENNIS SMURR

ASSOCIATE ADVOCACY DIRECTOR

FOR THE

PARALYZED VETERANS OF AMERICA

REGARDING S.1673

"THE MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT"

Chairman Mitchell and Members of the Subcommittee it is an honor and a privilege for me to present to you the comments and concerns of the Paralyzed Veterans of America regarding S.1673, a bill to amend Title XIX of the Social Security Act to assist individuals with a severe disability in attaining or maintaining their maximum potential for independence and capacity to participate in community and family life.

The Paralyzed Veterans of America (PVA) is a 41 year old veteran's service organization, chartered by Congress in 1971, to address the unique needs of this nation's catastrophically disabled veteran population. Our membership is not large, since to be a PVA member an individual must be a veteran and have incurred an injury or disease of the spinal cord which results in a varying degree of permanent paralysis. Because of this paralyzing condition, nearly all PVA members are mobility-impaired and must rely upon wheelchairs and other assistive devices for mobility. Many of our members must also rely upon family, friends, spouses, or other individuals to assist them in activities of daily living which they cannot perform for themselves because of their disability. This continuing need for personal assistance coupled with our knowledge of the cost of this care and devastating effects these costs can have on the disabled individual, his family and society in general, gives rise to our interest in the bill presently being discussed.

PVA's membership is comprised almost equally of service-connected and nonservice-connected disabled veterans. Our service-connected members are afforded monthly financial payments to compensate for their disability and reduced earning potential. They are also provided hospital and nursing home care, as needed, plus they are eligible to receive special housing grants to build, buy, or modify their personal residence to better meet their physical needs. Our nonservice-connected disabled members become eligible for a VA pension benefit if their personal income falls below certain income thresholds. They too are eligible for certain hospital and nursing home care, again if the need arises and certain qualifications are met.

PVA has over the years become a leading and effective advocate for the needs of physically disabled persons regardless of whether they are a PVA member, a veteran or simply an American with a physical impairment. We have attempted to break down many of the physical barriers that impede Americans with disabilities from regaining their rightful place in mainstream America. We work to dispell many of the myths which our society holds regarding the rights, abilities, and the potentials of Americans who have encountered a life-altering physical disability either by accident or disease.
PVA is extremely proud of all that we have been able to accomplish over the years.

PVA has been involved in dispelling myths and protecting basic civil rights because we are disabled Americans and part of a growing segment of our society who want to live our lives to the fullest, with all the privileges, dignities, and rights provided by our Constitution to other citizens of our nation. Our comments regarding S.1673, the "Medicaid Home and Community Quality Services Act" stem from this concern for equality, self-direction, and quality of life.

S.1673 and its predecessors have undergone a long and laborious evolution over the last five years when the concept of Medicaid reform was first introduced. The bill presently being discussed is not without fault or need of modification and the overwhelming need for a major reform of the long-term care provisions of the present Medicaid payment system is desperately needed and long overdue. Therefore, PVA is pleased to give its endorsement to the overall intent of S.1673. In addition, we commend the prime sponsors and numerous organizations representing the interest and well-being of citizens with developmental disabilities for having the dedication to forge S.1673 into the positive, far-reaching reform bill that it is.

Medicaid exists as this nations only publicly funded long-term health care program for persons with chronic disabilities. Medicaid eligibility varies from state to state but its criteria is based predominately upon the personal income and net worth of the applicant. The income threshold for Medicaid eligibility is at or below the national poverty level, therefore, for many individuals it exists as the resource of last resort. The provisions contained within S.1673 to assure that Medicaid beneficiaries are provided independent case management, individual and family support services (including respite and attendant care), specialized vocational services, protection and advocacy services, plus protective intervention are the types of services which are of critical importance to individuals with chronic disabilities who desire to live outside the traditional institutional setting.

The mere provision of funding for attendant care services in a community setting will go far toward assisting many thousands of disabled persons to live a more independent life style complete with the freedom and dignity afforded others in our society. In addition, if respite care services can be provided to those thousands of families that currently bear the total 24 hour per day, seven day per week responsibility of caring for a loved one with a chronic disability, then society will be accepting its rightful duty, and acknowledging the personal commitment and importance of the long-term care being provided by family members.

PVA must however, express its reservation about the inclusion of an age factor into the Medicaid formula for eligibility to receive these new services. We realize that cost considerations require that some age limit be established. We had hoped that the age of 35, as proposed in earlier bills, could have been maintained in this bill. This age cut-off would have better assisted those individuals, who because of accident or disease become permanently disabled before they work long enough to become eligible for the financial and medical support as provided for by the Social Security Disability Insurance (SSDI) program. With the present age 22 cut-off we create an undesirable situation of not being able to assist those chronically disabled individuals who may by reason of age inadvertently fall between the cracks of the two major federal programs established to help persons with disabilities.

The present bill partially addresses our concern about the age factor. It does so by incrementally increasing the age threshold by one year for each year the new law is in effect. An age 22 cut-off greatly reduces the potential population of new Medicaid service recipients. However, the fact remains that the existing Medicaid program is not age specific and to make these new services available only to those individuals who have had little or no chance to become eligible for the SSDI program makes S.1673 a disability specific type of legislation.

PVA would hope that the Subcommittee would reconsider the age eligibility issue and agree with us that those individuals with chronic disabilities between the ages of 22 and 35 need to be made eligible for new Medicaid services now rather than in the staggered fashion suggested by the present bill. The potential inequity and disservice that could result to those individuals who may fall between the existing SSI and SSDI programs could prove to be a very expensive proposition in itself not only in program costs but also in terms of lost earnings by those just entering their peak productive years.

Another item of concern to PVA stems from S.1673 granting program supervisory control to State Councils on Developmental Disabilities and in the creation of a new federal office of Developmental Disability Services. As we view this proposed Medicaid reform bill, the thrust of these new services is for increased independence, more freedom of choice, and the provision of more

Medicaid payable services in a community setting rather than solely through institutions. If this is the intent, then PVA would remind the Subcommittee that an independent living program has been in existence in this country for more than a decade and the benefits of linking the new services in this bill to on-going programs should be considered. The current independent living program is funded through the Rehabilitation Services Administration (RSA) under the mandate of the Rehabilitation Act. The blending of rehabilitation and habilitation programs should prove to be beneficial to all disabled persons and society in general.

service delivery systems of the Office of Special Education and Rehabilitation Services (OSERS).

The Subcommittee should know that OSERS has been mandated by the recent amendments to the Rehabilitation Act (P.L. 99-506) to better address the unmet needs of the developmentally disabled and mentally impaired population. Also included within those amendments was a requirement that each state develop a Council on Independent Living. It would seem logical to PVA that these State Councils be given supervisory authority over the programs envisioned by S.1673 rather than give such control to a disability specific entity. It should also be pointed out that while P.L. 99-506 gave RSA increased program responsibility it did not establish increased funding levels to carry out its new mission. Linking Medicaid funding of the services suggested by S.1673 to the on-going program responsibilities of RSA may be a financially sound mechanism to accomplish this end.

In conclusion Mr. Chairman, PVA endorses the overall intent of S.1673. We do have reservations with certain aspects of the legislation, namely the inclusion of the age 22 eligibility criteria. We would hope the Subcommittee would see fit to restore this critical element to age 35 based upon the considerations given earlier. PVA would also remind both the Subcommittee and the bill's primary supporters that just as long-term care is not disability specific, neither is Medicaid eligibility. Therefore, it is very important to remember that any effort to bring about something which everyone agrees needs to be done - reforming the present long-term care provisions of the Medicaid program - be done in such a manner so as to benefit all those at greatest risk or need, and not at the expense of

CUMBERLAND COLLEGE
WILLIAMSBURG, KENTUCKY 40769

April 14, 1988

United States Senate Finance Committee
Hearing on S. 1673 (Chafee Bill)
Medicaid Home and Community Quality Services Act

Gentlemen:

Oakwood Training Center, Somerset, Kentucky, is a larger facility (420 beds), operated by the state. It is excellent in program, personnel and product, as well as being a model facility itself.

Our daughter has been there as a resident for twelve of her forty-one years.

Small group homes and the like cannot provide adequate medical and proper specialized services for the seriously handicapped, who need physicians, nurses, speech and occupational therapists readily available on a repetitive and daily basis. Small units are not doing this now.

More and more confused misinformation on this issue is coming from Capitol Hill and from the Association for Retarded Citizens all over the country.

We veteran parents appeal to you not to throw the baby out with the bath water, but to eliminate from this bill all that mitigates against our larger facilities.

Please consider what was done years ago when our mental institutions were emptied out into the streets, giving us the homeless and all the problems they represent.

May you be given wisdom in your deliberations.

Sincerely,

Robert L. Palmer

Robert L. Palmer

The Dever Association
FAMILIES AND FRIENDS OF THE RETARDED FROM THE PAUL A. DEVER STATE SCHOOL CAMPUS

Senator George Mitchell
Chairman
Senate Finance Subcommittee on Health
United States Senate
205 Dirksen Guilding
Washington, D.C. 20510

Dear Committee Members:

The Paul A. Dever Association for the Retarded, a parent organization for the 500 residents of the Paul A. Dever State School for the Retarded. P.O. Box 631. Taunton. MA 02780, is opposed to the fundamental premise of the Chaffee bill S#1673,'Medicaid Home and Community Services Act of 1987', which is to undermine and eliminate facilities with a census greater than 15. We number over 350 members, representing approximately 1500 family members and have more than 30 years of advocacy experience.

The Chafee bill,and HR#3454 the Florio bill, has a deliberate anti-institutional bias and as presently presented

Denies right of choice of a safe campus environment in preference to a community setting which is more hazardous and stressful to severely and profoundly retarded individuals

Denies mentally retarded citizens a voice in this bill which'mandates' their future, without input or testimony from parents and guardians.

Limits options for concentrated quality of scale experienced and qualified medical service necessary for this needful population and forces acceptance of less specialized service.

While the idealogy of community homes has long been advocated for and supported by parents, prolonged development and inadequate service provisions have fallen far short of the need. Staffing, service programs, maintenance, and funding problems of larger facilities actually become more unmanageable and inefficient and costly when fractionated by community dispersement.

There are many cases in our organization of case failures in the community necessitating readmission to the state school environment for stabilization, where the service is focused.

The current chaos in mental illness treatment, caused by dumping and inadequate programs all over our country demonstrates very clearly what the consequences to our unfortunate mentally retarded citizens will be if they too are thoughtlesssly dumped upon ill prepared and resentful communities.

We disapprove of S#1673 and request that action and approval of this bill be deferred. Future revival should not occur unless the anti-institutional aims are eliminated, and there is active participation and inclusion of the views of free choice advocates.

The retarded and their families have already suffered too much to now blindly bring about a reversion in the quality care which now exists in large (necessarily so) treatment centers.

Sincerely yours,

William E. Powers Jr
William E.Powers, Jr.
President

PARENT EDUCATION PROJECT
UNITED CEREBRAL PALSY OF SOUTHEASTERN WISCONSIN, INC.
230 W. WELLS ST., MILWAUKEE, WI 53203
(414) 272-4500

April 6, 1988

Laura Wilcox, Hearing Administrator
United States Senate Committee on Finance
205 Dirksen Senate Office Building
Washington, D.C. 20510

Dear Ms. Wilcox:

I am writing to support the Medicaid Home and Community Quality Services Act (S.1673), which had a public hearing in the Sub-Committee on Health on March 22, 1988.

The Parent Education Project is a statewide, federally funded Parent Training and Information Project. (Our funds come from the Education Department's Office of Special Education and Rehabilitation Services.) Our purpose is to help parents advocate for high quality education for students with disabilities. We have been in existence since 1981, and served over 8,500 people last year.

In the 13 years since passage of the Education for All Handicapped Children Act, special education has made remarkable strides. Hundreds of thousands of children who would previously have been excluded from school are being educated. Through specialized instruction, young people are acquiring skills for which the 'experts' would have said 15 years ago that they lacked potential. Many students with disabilities are attending the same schools as their brothers and sisters, and in a growing number of schools, instruction is provided in the same classrooms so that students have chances to make friends with their nondisabled peers. Many high school special education programs teach vocational skills and provide actual job experience.

As a result, students and their parents approach graduation with the expectation that these young adults will find opportunities to use, and to continue to develop, the skills they have worked so hard for. They expect continued opportunities to relate to a variety of people, not just others with disabilities. They want to be able to participate in community life, like all young adults.

Too many graduates of special education find, instead, that their schooling is good only for a place on a waiting list. New graduates receive a lower priority for services than do people returning to communities from institutions. Wisconsin currently has over 5,000 adults on waiting lists for vocational and/or residential services. The 'institutional bias' of Medicaid is at the core of this problem. Until Medicaid dollars can be spent to support community-based services, the effectiveness of individual or systems advocacy is severely limited.

Our society has invested heavily over the last decade in developing the potential of young people with disabilities and welcoming them into the 'mainstream' of community life. The implied promise of public education is that it prepares people for meaningful participation in their society. In 1988, we are not keeping that promise or protecting our investment. S.1673 has the potential to do both, and for this reason, I strongly support it and urge the Congress to act on it.

Sincerely,

Liz Irwin

Liz Irwin
Project Director

LI:aa
cc: Senator Kasten
Senator Proxmire
Representative Moody

PENNSYLVANIA LEAGUE OF CONCERNED FAMILIES
OF RETARDED CITIZENS, INC.

April 14, 1988

STATEMENT FOR THE RECORD
on S.1673

Senate Finance Committee Hearing - March 24, 1988

S.1673, like prior proposed medicaid restructuring initiatives, concerns families of M.R. persons at home, in the community and especially congregate settings where the most disabled population usually resides.

Over the years, legislative proposals have reflected changes from an M.R. emphasis to a D.D. emphasis, to a more clearly defined but limited target population, and finally S.1673 addresses the long overdue quality assurance piece. Unfortunately, the "institutional" hang-up has not been resolved. S.1673 does not address case management, monitoring, advocacy and quality assurance for the institutional population because the hidden agenda is eventual elimination of this residential alternative. This bill continues to deprive the most debilitated of M.R. people of their right to quality treatment in a setting appropriate to their needs.

We are a voluntary advocacy organization. Among other services, we assist M.R. people and their families with the planning and placement process for C.L.A.s. We continue to be very much involved in problem solving for Pennhurst Class members who were Court ordered into small community settings. These people have had all possible protections: Federal Court oversight, attorneys who prevailed in favor of "the class" and ARC Pa., a supportive Commonwealth, the Pa. Department of Public Welfare, a Special Management Unit appointed by D.P.W. to oversee the program, (at one time) a Special Master followed by two Independent Hearing Officers, case management to plan and monitor at the County level, a grant to a university to monitor 20% of "the class" annually, a Pa. Developmental Disability Advocacy Network, etc. Yet we are in trouble! Please see:

Attachment #1 - Update, January 1988, Deinstitutionalization - The Record Speaks for Itself in Pa.
(a brief chronology of events to date, including reappearance in Federal Court by Plaintiff attorneys in the Pennhurst case with motions for contempt re: program deficiencies and inappropriate management of client funds.)

Attachment #2 - City of Philadelphia, January 6, 1988.
(Documentation that Pennhurst Class members were threatened with discharge due to monumental funding problems.)

In the case of Attachment #2, the Federal Court was not notified of the critical issues in the Philadelphia County system. Had there been no intervention, M.R. people would have been discharged without notification or opportunity to consent, and with no due process, to an unidentified location.

We do not feel that S.1673 would provide any better protection in the present instance. While it may be philosophically commendable, S.1673 lacks content that reflects a real knowledge of the real world of M.R. and what needs to be in place to avoid judgement errors now and in the future. It is of concern to families that information provided by "professionals" attests (nationally) to the positive results of the Pennhurst dispersal. However, a December 1987 report of the Temple University Research and Quality Assurance Group has provided information from their 1986 survey of parents that indicates:

1. Parents receive little systematic attention in the policy making process in the field of developmental disabilities. Families are usually relegated to the role of permission-giver.

2. Families of people in public institutions have been found to be very satisfied with their facilities.

3. Families who are satisfied with community settings maintain serious concerns about permanence of community programs and funding.

A sampling of negative comments from families involved in that survey include:

1. "The alleged monitoring is a colossal joke and should be done independently of D.P.W., the Commonwealth or County employees."

2. "I think [agency] is grossly negligent in client care."

3. "My boy is in a hospital for 10 weeks due to the fact his group home no longer wants to handle him because of illness. He was able to leave the hospital after two weeks but had nowhere to go."

4. "My husband and I feel that the staffing at [name] C.L.A. is a disaster. The outside of her C.L.A. looks like a ghetto dump."

5. "Staff turnover is drastic. Personnel only stay until they can get a better position. This has been for me the most discouraging aspect of community living."

On April 6, 1988 Federal Judge Raymond Broderick signed an order that establishes a May 20, 1988 deadline for a court approved professional team to investigate fiscal and programmatic conditions re: Pennhurst Class and submit a report to the Court.

Our Pennsylvania institutional dispersal was hastily implemented without adequate prior planning. We are in real trouble today because of inadequate funding and critical staffing shortages (both professional and direct care). In this state the administration is reluctant to admit that it is time to call a halt to the deinstitutionalization objective until we can adequately provide for those persons who have been relocated.

We urge the Senate Finance Committee not to precipitously endorse a national mandate for deinstitutionalization. A rational plan for change should address the multiple need of ALL M.R. persons without prejudice as to degree of disability, and how and where they will best be served. It should be a plan with built-in flexibility, which looks to parental concurrence, and which provides for independent advocacy and monitoring. Any new legislation should be guided by a long range plan for care with IDENTIFIED FUNDING. There should be an opportunity for full consideration of the objective by both the House and Senate.

Thank you for including our comments in this Record.

Polly Spare

Polly Spare, President,

Pennsylvania League of
Concerned Families of
Retarded Citizens, Inc.

Enclosures

ATTACHMENT # 1

PENNSYLVANIA LEAGUE OF CONCERNED FAMILIES
OF RETARDED CITIZENS, INC.
POLLY SPARE, PRESIDENT
P O Box 1133, DOYLESTOWN, PENNSYLVANIA 18901, (215) 348 4059 or (215) 348-4029

UPDATE

DEINSTITUTIONALIZATION

" THE RECORD SPEAKS FOR ITSELF IN PENNSYLVANIA"

January 1988

On October 30, 1987 Pennhurst Center discharged it's last resident, sixteen months after the June 30,1986 closure date specified in the Pennhurst Settlement Agreement.

Many Pennhurst Class members had been deinstitutionalized over objections without benefits and safeguards assured in Federal Court Orders as well as terms of the Settlement Agreement. Full due process was unattainable for these people without private counsel in spite of the Settlement, state and federal waiver regulations, and statutory law.

The Independent Hearing Officer named in the Agreement found himself powerless to enforce his directives. While he served, it was apparent that he had sincere concern for mentally retarded individuals and respect for federal court orders. He came to be viewed skeptically by both parties. Enforcement mechanisms were not available to him and plaintiffs and defendents were not yet prepared to acknowledge deficiencies. For most of 1987 prior to phase out his involvement was negligible. His contract with the Department of Public Welfare expired on June 30, 1987. HE HAS NO SUCCESSOR!

As reported in UPDATE, November 1985, Plaintiff ARC/Pa. and Defendents, including the Department of Public Welfare, were very much aware of deficiencies and abuse. Repeated urging by this agency on behalf of individual clients was not always sufficient to effect compliance. Even the Civil Rights Division of the U.S. Justice Department late in 1986 chose to ignore our request for an investigation. They had accepted our evidence several months prior to that time but , when advised by Pennsylvania authorities that our reports were exaggerated, they copied our submissions to all parties and returned our material without even a cover letter of explanation.

FINALLY!

On October 9, 1987, three weeks prior to closure of Pennhurst , Plaintiff Attorney David Ferleger filed a motion for contempt in Federal Court on behalf of all class members to compel appropriate management for their funds. He sought an order that Commonwealth and County defendents establish, impliment, and enforce guidelines necessary to ensure that funds are handled in accordance with state and federal law and Plaintiffs' (class members) constitutional rights. He also asked that there be an independent accounting of financial records, financial planning, receipts and expenditures of each class member since March 17, 1978. He states that any funds expended inconsistently with statutory law or the final Settlement Aggrement should be refunded to class members.

THEN

On November 16,1987, two weeks after closure of Pennhurst, Plaintiff Attorney for ARC/Pa. filed a petition on their behalf asking why Philadelphia County should not be held in contempt of the Pennhurst Settlement Agreement re: program deficiencies, inappropriate placements, health and safety issues. Their brief alleges that services to class members are deteriorating and that the underlying causes are systemic. They state in spite of per diems of $180 to $195 that:

57% of I.H.Ps are out of date
83% of clients are lacking one or more needed services
68% are lacking P.T./ O.T./ S.T.
35% of clients lack access to funds and benefits
38% of C.L.As have untrained staff
31% of C.L.As have staff vacancies
27% had medication errors

Their exhibits document serious deficiencies in services provided Philadelphia class members from failure to deliver services to outright abuse. They seek a programatic and fiscal audit by a team of three independent experts.

IN EACH INSTANCE THESE BRIEFS DO NOT ADDRESS PERSONS IDENTIFIED IN OUR ORIGINAL REPORT AND UPDATES.

Note: A hearing has been scheduled in Federal Court for March 7, 1988 to address Mr. Ferleger's complaint.

Philadelphia County Defendents have agreed to comply with P.I.L.C.O.P's request for a programatic audit by a team of three out of state experts.

RECENTLY

On January 6, 1988 the Philadelphia County M.H./M.R. Administrator advised executive directors of provider agencies under contract to that county that additional funds to offset programatic deficits will not be forthcoming this year unless the Pennsylvania Legislature or the Governor's Office make them available. Providers who cannot eliminate cost items consistent with client welfare and safety were advised to prepare discharge plans and terminate programs when funds run out. The Federal Court was not notified.

NO MENTION WAS MADE ABOUT WHAT WOULD OR SHOULD HAPPEN TO CLIENTS INVOLVED- MOST , PERHAPS ALL OF WHOM ARE BOTH 2176 WAIVER AND PENNHURST CLASS.

It is reported that there are 1000 priority level placements awaiting resolution in this region of Pennsylvania. A favorable outlook for further safe and responsible deinstitutionalization of these people seems grim in light of staffing and funding deficiencies. Should Philadelphia County prevail in the pending court actions, the impact of providing funding for that area will undoubtedly prove detrimental for surrounding counties who will be forced to further share their limited resources.

MEANWHILE

WHAT HAPPENED TO PEOPLE AFTER NOVEMBER 1985 ?????

L.S. He remains in the same C.L.A. program. Subsequent to the last UPDATE it was determined that his provider agency had been sending residents of that facility to day programs without breakfast. They claimed to have insufficient funds for food, $75/week including household necessities, for three adult males. The Independent Hearing Officer took an active role in this case. In June of 1987 his parents were called at midnight with a request to take him home-" a staff person sat on him face down". He remained with his family for four months. It is reported that there are s signs in his apartment directing staff not to eat any food.

NOTE: The family of a second resident in that C.L.A. very recently contacted our agency requesting help re: excessive weight loss and abuse.

****

M.S. He remained at Pennhurst until October 1987, one of the last five residents to leave. His ICF/MR placement appears to be "appropriate" for his needs. Mrs. S. has been diagnosed terminally ill and our agency has, at her request, helped to plan for his transfer, will monitor the placement and has provided a guardian ad litem for a pending Federal Court action.

****

D.B. She was eventually assigned to a 4 hour work day, is now 72 years old and still involved over her continuing objection in THE SAME PROGRAM! In December of 1987 she was given a new goal objective-"she will increase productivity by 20% within 6 months". D.B. can sort 4 objects. This woman is a recipient of Home & Community Based Waiver Services and as such should be entitled to a choice of day provider. There is no longer a hearing officer to mediate and Philadelphia County is long overdue in developing an appropriate peer oriented program for it's mentally retarded senior citizens.

****

J.N. He left Pennhurst very reluctantly in December 1986 with assurances and "plans" for community employment that were not implemented. He spent a very traumatic ten months in a workshop setting. J.N. is finally is a transitional work placement. The program is smaller and basically heis happier but he still does not earn the $75/ week available to him at Pennhurst. Ongoing plans for competition for this special olympics grand champion have not materialized.

****

M.G. She returned to her older sister's home in the fall of 1986. Acceptable community alternatives were never made available for her - not even a day program.

****

P.H. Between November 1985 and February 1987 she was relocated three times. Her C.L.A. finally sent her in restraints by ambulance to a mental hospital because of behaviorial outbursts. Within hours she was court committed to the M/R. unit of that facility without prior notification to her mother who is a court appointed legal guardian. She lived there for one year, participated in a behavior modification program and was at all times FREE of controlling medications. During her fourth month, she was allegedly raped. After that incident several months were spent negotiating her present placement which appears to be a most appropriate (hopefully permanent!) setting for this woman. To date , she continues to function with no need for psychotropic medication and is not involved in behavior modification.

****

Dispersal of the Pennhurst Class has not been as positive a process as it's advocates have projected nationally. Selective reporting has enhanced the ~~desired~~ image. Overlooking the negatives has violated client rights and done nothing to make the system more accountable. Our experiences as advocates highlight a need for:

1. Guidelines establishing quality assurance and a mechanism for assuring quality
2. An open mind re: types of habilitation that best meet the needs of a diversified MR population in cost effective programs that may include congregate facilities for some people
3. An available and enforceable due process proceedure independent of the provider system
4. Independent monitoring and advocacy

THE FINAL CHAPTER IS YET TO BE WRITTEN !

ATTACHMENT # 2

CITY OF PHILADELPHIA

DEPARTMENT OF PUBLIC HEALTH

OFFICE OF MENTAL HEALTH AND
MENTAL RETARDATION

One Reading Center
1101 Market Street — 7th Floor
Philadelphia, Pa. 19107-2907

MAURICE C. CLIFFORD, M.D.
Health Commissioner

JOHN M. CIAVARDONE
Administrator
Mental Health/Mental Retardation
Program

January 6, 1988

Executive Director

Dear

The costs of operating your Mental Retardation Programs exceed the State allocation received by the Office of Mental Health and Mental Retardation to be made available to you. Our numerous requests for additional mental retardation funding to meet the costs of court-ordered and emergency placements and the actual costs of maintenance programs have been denied. As you can see from the attached copy of a letter from Secretary White, there is little reason to expect that additional funds to offset your deficits will be forthcoming in this year, unless the General Assembly provides additional funds, or additional funds are made available through the Governor's Office.

Consequently, you must continue to try to hold down expenditures wherever possible and also to eliminate cost items, consistent with client welfare and safety. If you cannot bring costs to within the level of available funds and still secure the safety of individuals in your care, you are hereby instructed to terminate your programs when the funding has been exhausted. This highly regrettable choice is made necessary by the State's long-time failure to recognize the real costs of care, and is the only decision we can make and still protect the interests of our clients. The City of Philadelphia cannot assume financial obligations that are the legally mandated responsibility of the Commonwealth of Pennsylvania.

You must provide written notice to this Office immediately regarding the programs which will be curtailed or closed, the specific program activities and/or sites affected, the specific last date of operation, and the clients to be discharged. Our Case Managers and/or Program Analysts will then be in contact with you to develop appropriate discharge plans for the clients. If you have sufficient funding to complete the current year without incurring a significant deficit or jeopardizing the clients through inadequate care, please advise us of these facts in writing. Such a letter should be signed both by the Executive Director and the Board Chairperson. ✓

Consistent with the terms of our current contract, if your operating expenses have already exceeded your allocation, you are to consider this letter notice of the unavailability of funds.

Your cooperation in this effort will assure as smooth a transition as is possible under the circumstances and will be greatly appreciated.

Sincerely,

John M Ciavardone

John M. Ciavardone
MH/MR Administrator

JMC:a:tat

Monday, Feb. 29, 1988 The Philadelphia Inquirer

A motion to help the retarded

Court aid sought in service crisis

By John Woestendiek
Inquirer Staff Writer

Saying his clients are "caught in a crisis not of their making," an attorney representing former residents of Pennhurst will ask a federal judge today to prohibit their discharge from programs administered by Philadelphia's financially troubled community mental-retardation system.

The development is the latest in a budget crisis that the city has predicted could halt services to an estimated 1,200 mentally retarded people, many of whom are former residents of the Pennhurst Center, a state institution for the mentally retarded that closed last year after a lengthy lawsuit.

David Ferleger, the attorney who brought that suit, planned to file a motion before U.S. District Judge Raymond J. Broderick today asking him to ensure that ex-Pennhurst clients are not discharged from programs.

The motion also reportedly will ask Broderick to appoint a special master to review the causes of the financial problems in Philadelphia's mental-retardation system, and an administrative expert to recommend possible short-term solutions.

The city Office of Mental Health and Mental Retardation, facing a deficit it says is at least $5 million, has instructed the nonprofit organizations that provide mental-retardation services for the city to shut down when their funds run out.

In response, 23 of those agencies have notified the city that they will have to close more than 100 of their programs before the fiscal year ends on June 30.

Three of those agencies had planned to shut down programs today. But the closings, which would have been the first, were averted when the state Department of Public Welfare allocated $223,000 in emergency funding late last week. The programs included two group homes and respite-care facilities that, together, served 20 mentally retarded people.

Still more closings are predicted in March, April and May, unless the city is able to secure additional money from the state, which provides the bulk of funding for community mental-retardation programs.

Without financial help, the city has said, some retarded people may have to be returned to institutions, or, as expressed in one internal report, "streeted."

"They can't dump my clients into the streets, and they can't dump them back into institutions," Ferleger said yesterday. "Neither is acceptable. They both would be an insult to the 14 years of this lawsuit."

City officials have told the state they need as much as $6.4 million to keep programs operating through the fiscal year, and have blamed the deficit on historically small increases in state funding, increased operating costs and unexpected expenses.

State welfare officials, meanwhile, have said that, although only limited funds are available, they will continue to meet and cooperate with the city. A meeting between city officials and state Welfare Secretary John F. White Jr. is scheduled for tomorrow.

"There appears to be a political struggle going on, and the clients are caught in the middle of it," Ferleger said.

"It's hard for me to know whether the crisis is as great as the city says it is or as manageable as the state says

(See PROGRAMS on 4-B)

Aid sought for retarded

PROGRAMS, from 1-B

it is," he said. "That's why I think the court has to sort it all out."

According to a copy of the motion Ferleger said he would file today, Pennhurst residents, who by and large have prospered since leaving the institution in Chester County and moving into community programs, now face uncertainty. "Nobody knows how long they will live in their home or go to their jobs and day programs."

It asks that an expert be appointed by the court to help the city get through the current budget crunch, and that a special master be appointed to review the system and recommend long-term solutions.

Under the settlement of the Pennhurst lawsuit, the state and counties are required by the court to provide services to former Pennhurst residents. Theoretically, halting services would be in contempt of that court order, Ferleger said.

Two other motions are before Broderick in the Pennhurst case, hearings on which are scheduled for March 7. One contends that the state and counties have failed to require adequate controls on clients' funds. The other says that conditions in group homes in Philadelphia are inadequate.

BEST AVAILABLE COPY

EXCERPTED FROM

THE PHILADELPHIA INQUIRER FEB. 17 1988

Mentally retarded face cutback in city services

At least 26 of the 33 local nonprofit agencies that provide mental-retardation services have notified the city they will be forced to close or cut back before June 30. And the city is advising them to shut down.

Taken together, the agencies' projected deficits total $6.4 million. The state Department of Public Welfare has told the city that it may be able to provide an additional $1.4 million, which would still leave a $5 million shortfall.

State funding for mental retardation programs in Philadelphia increased by 4.5 percent this fiscal year, 3.25 percent in 1987, 3.75 percent in 1986 and 4 percent in 1985. The city mental retardation office, which allocates money to the agencies, received $62 million in state funds this year, $3.5 million in federal money and $3 million from city general fund.

Halting services to the people who had lived at Pennhurst would be in a violation of an order issued by U.S. District Judge Raymond J. Broderick.

"I am astounded that the city would order providers to dump clients from programs without first seeking the aid of the court," David Ferleger, an attorney for Pennhurst residents, said in a letter to the city last month.

March 30, 1988

The Finance Committee:

My daughter, Claudia Ann Prator, a client at the Fort Worth State School, enjoyed "Home and Community Services," as you point out in HB 3454/SB 1673. She was at home with her mother and father. Claudia enjoyed the public school in Dallas, Texas, until she was 17 years of age. We did not place her in the STATE SCHOOL and forget her when she was a baby. Her physical disability would not permit her going further.

After more than two years of being home, with both mother and daddy working, Claudia needed more than we could give her. Denton State School was being completed. Mr. Prator and I discussed the situation with her and she made the choice herself. Claudia has enjoyed her home every other week end. She enjoys the holidays at home. She enjoys the "FAMILY REUNIONS" and she enjoys a vacation every year. She has as much a COMMUNITY LIFE as can be afforded and I might say, probably more than in one of the community places. Not having any brothers or sisters the State School is the best place for Claudia.

The HB 3454/SB 1673, Medicare Home and Community Quality Services Act of 1987 should have more consideration before going into existence. There will be more "child abuse." I do not understand the reasons for a change since we have been going along very nicely for more than 20 years. It will cost more to maintain such places. We already have our buildings and grounds around and everything to accommodate the clients WHY THE CHANGE? What will become of the facilities we now have?

Mr. Prator has been gone 18 years and the time is closing in on me. I would be happy to know that my daughter is left where she is, content with her friends, some she has been with since she was six years of age. PLEASE DO NOT DISTURB THIS RELATIONSHIP.

I believe if you people who are trying to make these changes had a handicap child or had any relation with one you could understand the PARENTS of these clients. WHY NOT LEAVE THEM BE?

Sincerely,

Dora Prator

Dora Prator
623 Athenia Way
Duncanville, Texas 75137

DMP/s

April 5, 1988

Ms. Laura Wilcox, Committee on Finance
U.S Senate, 205 Dirksen Bldg.
Washington, D.C. 20510

Dear Ms. Wilcox:

I am opposed to Medicaid Home and Community Quality Services Act - Senate Bill 1673

The time has come to put compassion and common sense before monied interests. More than two decades of mass deinstitutionalization of mentally ill and retarded people have proven this program to be a failure. Why? For all but the mildly retarded, who are definitely in the minority, it is unworkable.

Community living has been a disaster for the vast majority of the mentally handicapped, as evidenced by untold cases of suicide, disappearance, death in group home fires, rape, sodomy and exploitation. Add to this the miseries of hunger, homelessness, lack of medical care, psychological abuse and exposure to the dread disease Aids. Many of the mentally impaired are forced into crime in order to survive and, as a result, put into another institution called prison, certainly inappropriate for them. Others, who are dangerously aggressive and who repeatedly commit crimes in the community, are counselled for awhile under the present system only to be turned out again and again to repeat the same or a worse crime.

I agree, retarded citizens who are able to work, attend school or adjust well socially should be welcomed into community living. Most of them haven't been institutionalized in the first place.

Our chief concern should be the helpless handicapped. Many scattered facilities for them cannot be properly monitored. They are at the mercy of community care operators in business for profit, who don't hesitate to cut services, food, etc. in order to increase profits. Moreover, misappropriation of funds is commonplace. Retarded persons suffer the same ill-treatment as the abused children about whom we are all concerned. Unfortunately many of them are unable to speak. Most don't know how to report a crime.

Even the best community homes cannot offer the services provided by large state institutions which have doctors, nurses and staff trained to meet the special needs of our special people. All services considered, many small facilities are far more costly to operate than is centralized care regardless of what private vendors may claim. Tax payers have already paid for our large state institutions. Profoundly retarded persons and those with severe physical problems need them. All need the security they provide in this age when our big cities are virtually jungles.

Senate Bill 1673 would force the closure of large state institutions. My profoundly retarded son is a client in one of them. As I grow old my fear increases lest he be thrust into a hostile community. He can neither speak nor take care of his most basic needs; he won't defend himself; he would not self-preserve in an emergency. I need the assurance that he will always have the safety, the quality care, special programs, and the least restrictive environment of the large state institution with its spacious campus, lovely park and playgrounds.

Closing our large state institutions is not only poor fiscal policy, it is cruel. Too many retarded citizens have already died or suffer under community living. Please do not add more. DEFEAT SENATE BILL 1673.

Sincerely yours,

Alice M. Ritter

Alice M. Ritter
2769 Teakwood Dr.
N. Fort Myers, Fla. 33917

April 15, 1988

Ms. Laura Wilcox
Hearing Administrator
Committee on Finance
Dirksen Senate Office Bldg., SD-205
Washington, DC 20510

Dear Ms. Wilcox:

I myself am not a parent, but I am a sister of a severely handicapped 15-year old boy. I am writing to you on behalf of my brother and on behalf of Augustana Center located at 7464 N. Sheridan Road in Chicago, Illinois.

During the past two years that my brother has been at Augustana, I have learned to appreciate the special concern of everyone that is involved with handicapped children. For many years I only witnessed my brother's disabilities and I knew nothing of special centers for handicapped children.

It has come to my attention that Bill #1673 (Medicaid Home and Community Quality Services Act of 1987) if passed could result in closure of Augustana Center and Misericordia in Chicago -- the only two large centers in Chicago.

I am deeply disturbed by this ... I can't even imagine what would happen if this bill was passed. I am horrified to think of what would happen to the children, we must protect these centers at all costs.

Augustana Parents Group represents 150 special handicapped children and adults and we are strongly holding on together to protect the handicapped from being ignored, from taking away their homes and from a better life at the centers with special care and attention devoted to them.

We would like your response to our request, for it is very important that we know what kind of future lies ahead for our handicapped children and adults. I understand it takes a great deal of time and effort for a good result, but our handicapped do not have a lot of time, and they need all the assistance they can receive from people who care and are willing to help.

Thank you for your consideration. I look forward to hearing from you.

Cordially,

Yolanda Rocha

Ms. Yolanda Rocha
2329 W. 21st Place
Chicago, IL 60608

March 17, 1988

RE: S. 1673 -

Medicaid Home and Commmunity Quality Services Act of 1987

Hearing Scheduled- March 22, 1988 before the Senate Finance Subcommitte on Health

Senator George Mitchell and Members of the Committee;

I am the mother of two children, our oldest daughter Jamie, who is now six, was diaganosed with mental retardation at age 2 1/2. I am writing today in support of S. 1673! For the last three years we have tried unsuccessfully to get in-home support for our daughter Jamie. After exhausting every avenue that we knew of to get help and realizing we could no longer cope with the financial, physical and emotional stress. We had to place Jamie in a foster home 4 months ago. This has been a very emotional process for our family!

Our family is at the point of total frustration with the system. WE WANT JAMIE AT HOME! We feel that there is something drastically wrong with the system when the majority of the incentives encourage placement out of the home. For over 2 years we've tried in vein to get support services for Jamie and ONLY 3 days after reaching the emotional decision of placement as the only alternative for our family, placement was arranged and the system was willing to pay the monthly care costs for foster placement!

We really fought hard to keep Jamie at home, I tried to find day care last summer out of despiration, hoping to return to work to help pay off some of the bills, totalling over $5,000, but after 2 months of rejection I gave up, no one wanted the responsibility for Jamie because of her need for constant supervision.

Now that Jamie is out of home she receives Medical Assistance,SSI and free school lunches, but if she were at home because of Bill's income, she would not qualify! We are one of the families that always seems to fall between the cracks, a couple of thousand dollars to much to qualify for assistance, but not enough for a family of four to get by on!

As hard as it was dealing with all the responsibilities of Jamie at home it is equally as difficult in a different way not having her with us! In some ways we really feel that we are slowly loosing control of our own daughters life, not by our choice. We are not asking for alot, but we need support services for Jamie. Through no fault of her own, Jamie will not have the opportunities and experiences of normal children, please give her the opportunity to come back home!

We desperately want our family back together again! We hope you will seriously consider the passing of S. 1673 - the Medicaid Home and Community Quality Services Act of 1987 AND HELP BRING JAMIE HOME TO STAY!

Thank you for your consideration,

Cindy S. Scattergood

Cindy Scattergood

April 16, 1988

Laura Wilcox, Hearing Administrator
U.S. Senate Committee on Finance
205 Dirksen Senate Office Bldg.
Washington, D.C. 20510

Dear Ms. Wilcox:

The purpose of this letter is to state my support for the passage of the Medicaid Home and Community Quality Services Act (S.1673 and R.H. 3454).

I feel that this is a very important piece of legislation for people with developmental disabilities. If it passes, it would allow them to live a more productive and independent life of a better quality. The passing of this Bill would allow these people to live in the community rather than in an institution. This would allow them to have more freedoms and opportunities. to learn skills that would teach them independence.

Sincerely,

Scott Schoeckert

Scott Schoeckert
13050 Marquette Drive
New Berlin, Wisconsin 53151

March 25, 1988

Ms. Laura Wilson, Hearing Administrator
United States Committee on Finance
Room SD-205 Dirksen Bldg.
Washington,D. C. 20610

Reference: Press Release #H-13 Feb. 26, 1988 Paragraph 12 Written Statements concerning Comments and Concerns Regarding S1673 - The Medicaid Home and Community Quality Service Act.

Senator George Mitchell, Chairman ofthe Senate Finance Subcommittee on Health.

Community based services for the Developmentally Disabled is a noteworthy successful concept for a sizeable portion of this specific population. This commendable program IS NOT ADEQUATE for an equally sizeable number of the Developmentally Disabled who require the extensive services of facilities such asHoly Angels Residential Facility for the Mentally Retarded, located in Shreveport, Louisiana (179 Residents) where our son is a progressive and happy citizen with the support provided by the extensive staff and facilities available.

We have reached this conclusion after making, within our very limited means, an extensive evaluation of the Community Based Services vs large facilities service in three states: Texas, Louisiana and California.

1. This bill would serve the total community if it were amended to provide, **WITHOUT RESTRICTIONS**, THE SAME LEVEL OF SPENDING AS PROVIDED FOR COMMUNITY GROUP HOME SETTINGS for those requiring the array of services found only in large ICF/MR Facilities.

2. **PARENTS OR GUARDIANS** must have a major roll in choosing the living arrangements appropriate for their responsibility providing the persons involved are incapable of making his or her own decisions.

3. It is possible the bill as currently presented, in spite of its good intentions,may be judged to be **GROSSLY DISCIRIMINATORY** and in violation of the **CIVIL RIGHTS** of that portion of the community represented bythe Developmentally Disabled requiring the care and services provided by larger ICF/MR's.

Respectfully Submitted,

Lois F. Stroup
Lois F. Stroup

Ralph F. Stroup

800 Brazos, Graham, Tx. 76046

COMMITTEE ON FINANCE
United States Senate
205 Dirksen Building
Washington, D.C. 20510

April 15, 1988

TO: Finance Subcommittee on Health

SUBJ.: S.1673 The Medicaid Home and Community Quality Services Act of 1987

RE: Freezing of Funds to IMC/MR Facilities

Dear Senate Committee Members:

I applaud your proposal to address the full spectrum of needs of those with disabilities and your goal to see more community based living, educational and social facilities. For the majority of mentally handicapped individuals, the goal of small group homes and reaching the maximum performance levels is a real thrust in our communities.

However, your desire to limit funds to institutions in the effort to encourage growth of community based living overlooks a segment of the mentally handicapped population which few citizens are aware exists. This is the profoundly retarded (IQ's below 20) individuals who will never be able to benefit by living in a group home setting. Their needs are intense and often medically complicated. They often do not require the intensive care that hospitals offer, but are so involved that they do require round-the-clock care, ideally in a facility larger than a group home but smaller than institutions.

These facilities must be staffed with registered nurses and trained personnel, and ideally handle 30 to 60 beds. This allows for cost effective, personalized care in that the facility is small enough for all personnel to know each of the residents while being large enough to afford necessary, specialized equipment and attracting medical personnel to make "house calls".

One example of such a facility is Kradle Kare in Maitland, Florida. My thirteen year old daughter, Rebekah, has lived there for the past 4½ years. Although an unusual situation, it was my social worker who recommended and arranged the placement. Until the Friday morning in December, 1983, when she called my home, I did not even know about Kradle Kare. By the following week, Rebekah was living there.

The reasoning behind the social worker's decision was that this was her opportuntiy "to save a family." You see, many parents are raising their handicapped child alone. Their spouses, parents and friends can't handle the "unnormalness" of their situation; and without meaning to be unkind, they just don't call or know how to react when they are together.

The benefit of residential placement to a family is that there is life beyond the handicapped child - that siblings can at last participate in sports, go to lessons, have friends over; and the family can go shopping or out to eat together without having people stare, and without having to schedule the most mundane outing around the special needs of the handicapped child. After all, changing the diaper of a grown child in a public restroom is just not viewed as "cute".

Quite honestly, I feel guilty that my family is fortunate enough to have placement for Rebekah when so many families, especially the poor and single parents have nothing. Due to the fact that they must be available during non-school hours, these parents are hindered in what jobs they may take and therefore, their incomes are limited.

And what of a family when a catastrophe occurs? As it turned out with us, Rebekah's placement could not have happened at a better time. Shortly thereafter, I was diagnosed with cancer and had to submit to extensive surgery and radiation. What would my family have done had Rebekah not already been living at Kradle Kare?

There is another area which needs to be addressed. What is a family to do when job changes or transfers occur? Rebekah had been on a residential placement waiting list in North Carolina prior to our move to Central Florida. Ofcourse, the facility was still seeking funding and had not even broken ground yet. Then, we moved, excluding us from that list. I am very satisfied with her placement here, however, my husband had an excellent career opportunity in the southern part of the state, more than 200 miles away. We moved, thinking that we could move Rebekah also, but so little information was available. Its a big secret where these facilities are and who they accomodate; and its a long drawn out process of having this district of HRS send records to that district of HRS for review. Then, a two year waiting list exists. Worst of all, HRS representatives do not even say where the facilities are or give the opportunity to tour them before placing your child on a waiting list. This all takes place after many long distance calls and finally reaching the magic "informed source".

In determining whether to accept a job transfer, most families research schools, living standards and housing in their potential new community. With a profoundly handicapped child, an involved parent wants facilities nearby so as to afford the family the opportunity to maintain continued contact.

In order to maintain contact with my daughter, who cannot speak, see or understand what is being said (thereby eliminating phone calls and letters) it was necessary for me to drive 200 miles each way every two to three weekends. In this manner, I was able to observe my daughter's care and take her to specialists. However, this travel was a drain on my other children, not allowing them to fully participate and feel part of our new community. This had just the opposite effect of what my social worker had tried to achieve. Finally, my husband and I felt it was necessary to move back to Central Florida so as to assume some normalcy in our family. The stress of moving frequently and feeling confined to a certain locale has hindered our family life and my husband's career.

Please, Senators, reconsider the freezing of monies for Intermediate Care Facilities for the Mentally Handicapped. If anything, we need more such facilities. This would provide care for the child while still being close enough to a family's town so that they can participate in the care and lives of their children. This is a little known segment of our population which has a tremendous impact on their families and respectively, their communities. Too many families are homebound for lack of care facilities and must bear a burden that was to have been a "bundle of joy".

Respectfully,

Lois D. Smith

Lois D. Smith

THE HOME AND SCHOOL ASSOCIATION
of the
Southbury Training School
Southbury, Connecticut 06488

March 17, 1988

Finance Subcommittee on Health
Committee on Finance, U. S. Senate
205 Dirksen Building
Washington, D.C. 20510

Re: Senate Bill 1673

Dear Sirs:

On behalf of the more than 1,050 residents of Southbury Training School and their parents and friends, we would like to voice our opposition to S. 1673 as presently written. We sympathize with your vision of including everyone who is handicapped, regardless of the time the handicap started, in the pool of persons to be helped by Medicaid funds, even though this may add more than one million persons to the rolls. However, we consider the cap on funding to persons who live in institutions to be discriminatory and most unfair.

At present, 75% of our residents are severely or profoundly retarded; when the Southbury population reaches the suggested level of 825, almost 100% will be in those categories. Their parents and guardians overwhelmingly (87%) want them to remain at Southbury.

Why should our relatives, who have the most serious handicaps and need the most care, be cut off from federal funding unless they move into the community? Would you refuse to fund seriously ill persons who are in an intensive care unit unless they move into a nursing home?

We appreciate that most of the retarded can and should move into the community, but it must be acknowledged that some cannot and should not. And it should also be acknowledged that parental choice should have a vital role in making such decisions. Freedom of choice is an important part of our American heritage.

Please amend this bill so that community placements will be offered to all who can and want to be there, and institutional beds will be supported in the same manner for those who are better off in congregate settings. You do not have to harm our children in your efforts to help other children.

Sincerely yours,

Sarah E. Bondy

Sarah E. Bondy, President
Home & School Association

Manlius, Illinois
61338-0014
March 20, 1988

Ms. Laura Wilcox, Hearing Administrator
Committee on Finance
Dirksen Senate Office Building, SD-205
Washington, D.C. 20510

Dear Ms. Wilcox:

This letter is in regard to S. 1673.

Some facilities were started by churches. Why should they be closed when therapy, care, training, and counseling are given so the residents' potentials can be developed?

Congressmen use the statement that they're interested in creatine opportunities for disabled individuals to be independent and self-sufficient. Do they realize that the personnel working in good large facilities have training and know the capabilities of each resident and help them to develop their capabilities? Do they realize that the conditions of many of the residents, in good large facilities, are such that they can never be independent or self-sufficient?

How many Congressmen or Congresswomen have ever visited a good large facility to see the severely handicapped residents and to observe the excellent care and training that are administered?

Some residents have been in good large facilities almost all their lives and would be frustrated and even regress if removed from routine. Is Congress aware of the fact that everyone cannot be mainstreamed?

Why should Congress, so unaware of each individual in a good facility, decide where an individual should be when parents, family, and the individuals are happy in the good facility? Is Congress aware that the handicapped are happy with members of their group in a good facility where there is structure, care, and therapy?

How many members of Congress have a handicapped child?

Is Congress aware that residents who can be moved to independent living facilities are being moved?

I have heard of different individuals, who after having been home for a visit, were happy to return to their good facility where there was structure and friends.

BEST AVAILABLE COPY

Certainly Congress is not considering the cost of S1673 or the care of the handicapped. Does Congress wish to put the burden on the local communities? Is Congress aware of the expense in having group homes of 15 or less and providing all the care, training, supervision, and therapy that are available in a good, existing large facility?

Is Congress aware that there is a waiting list at good, large Christian facilities? Is Congress aware that parents placed their handicapped loved ones in these good facilities so they would have care when they, the parents, were gone?

Does Congress recognize the need for continued large facilities for the future? Consider the cases of cerebral palsy, multiple sclerosis, mental retardation, and physical problems to name a few?

Why close good existing facilities when the parents & residents, are happy with the care, structure, training, and therapy at the good facilities?

A Concerned Citizen for the Handicapped,

Leona Swan

Leona Swan

by

Richard Johnson

Texas Association of Private ICF-MR Providers
Statement on the
Medicaid Home and Community Quality Services Act
S. 1673

April 15, 1988

The Texas Association of Private ICF-MR Providers (TAPP) is an organization of individuals, nonprofit entities, and proprietary companies that operate intermediate care facilities for persons with mental retardation and related conditions (ICFs/MR). Since its foundation, TAPP has included in its membership 80 - 99% of the privately provided ICF-MR certified beds in the state of Texas.

The Texas Association of Private ICF-MR providers is vitally interested in the efforts to reform Medicaid service delivery through the Medicaid Home and Community Quality Services Bill (S. 1673). S. 1673 has garnered widespread support from consumers, advocates, professionals and service providers because it will allow the Medicaid program to fund an array of family and community support services for persons with disabilities—services currently available only under the cumbersome uncertainty of the home and community-based waiver process. As such it corrects what has been described as the institutional bias of the Medicaid program. Furthermore, it has drawn support because it will eventually broaden eligibility for these family and community support services to all persons with severe disabilities.

While recognizing the potential opportunities this bill offers to persons with severe disabilities, the Texas Association of Private ICF-MR Providers opposes the bill as it is currently formulated. TAPP supports amendments to the bill to prevent regrettable unintended consequences to the service delivery system and those dependent on it if the bill is enacted without modification.

There are currently two ICF-MR programs in the state of Texas: the institutional program and the community-based program. The institutional program is made up of large state institutions, many of which have a long history in our state. The community-based program was developed during the past fourteen years under the Medicaid program to provide cost-effective, community alternatives to state institutions. Private sector providers has stepped forward and developed a range of community facilities under the Medicaid program to assist the state in providing needed services for persons with mental retardation and related conditions. The cost-effectiveness of the program is evidenced by some of the lowest reimbursement rates in the country. The community-based program has served the state well as evidenced by facility costs that are virtually one-half those of the state institutions and by an excellent record of service provision.

Many of the people served in the community-based program reside in facilities that have sixteen or more beds. Currently the program includes 36 such facilities serving over 2500 individuals. These facilities are largely funded under Medicaid and represent substantial personal, professional, and financial commitments to provide quality services to eligible individuals. S. 1673 as currently formulated poses a serious threat to the continued existence of these facilities and to the continued services to persons who reside in them.

I Existing Private Facilities.

The best known manifestation of the threat to facilities with 16 or more beds is the freeze on payment for services in such facilities in Section 4 of the bill.

Senator Dodd, one of the bill's cosponsors, noted in the Congressional Record that he was "somewhat troubled by the bill's provisions that would cap Medicaid dollars for institutions at their level in 1988, except to the extent that the cost of living exceeds 6 percent thereafter. The result would be that funding for institutions would be reduced to about half of today's value within 15 years. That level will make it hard to continue to assure quality care for residents of institutions."

One special difficulty faced by large private facilities is that they will have to compete with large state institutions for what amounts to a shrinking pot of federal dollars. Since the state sets the Medicaid reimbursement rates and promulgates and enforces Medicaid regulations, private facilities may be put in a disadvantaged position in relation the shrinking amount of federal funds—a situation that may lead to a spate of Boren admendment litigation on behalf of privately operated facilities.

A lessor known but even more devastating manifestation of the bias against facilities with 16 or more beds is the bill's requirement to depopulate larger facilities through diversion of potential admissions and the transferring of individuals who currently reside in them.

Proposed amendments to Section 1921 require the state to develop home and community support services for all individuals needing services:

> "Section 1921.
> (c) STATE REQUIREMENTS.—In order to receive payment under section 1903 with respect to community and family support services provided under the State plan to any eligible individual with a severe disability, such plan shall provide that the State—
>
> "(9) ensure that any individual with a severe disability for whom a public agency (or an agency under contract with a public agency) arranges a residential placement is placed in a foster family home or community living facility that is located as close to the home of the natural, adoptive, or foster family of the individual as is consistent with the best interests of the individual . . . ."

Similarly, the proposed state implementation strategy requires the state to divert persons from facilities with 16 or more beds:

> "(4)(A) in the case of individuals with a severe disability who are living in residential facilities which are not family homes, foster family homes, community living facilities, provide that—
>
> "(i) admissions to such residential facilities are restricted through the use of community and family support services . . . ."

The newly proposed state implementation strategy requires the states to develop an aggressive plan to transfer persons from facilities with 16 or more beds including those certified to provide active treatment (facilities certified in accordance with section 1905(d), ICFs/MR):

> "(E) set forth specific objectives and a projected schedule, over the succeeding five-year period, for transferring individuals with a severe disability (who are residing in a facility described in subparagraph (A)(ii) and are not transferred pursuant to subparagraph (D)) to more appropriate residential setting where they will be eligible to receive community and family support services;
>
> "(F) provide that in transferring any individual with a severe disability from a facility described in subparagraph (A)(ii)—
>
> "(i) such individual is transferred only to a facility or program that is capable of providing an appropriate array of community and family support services (or in the case of an individual transferred to a facility certified in accordance with section 1905(d), active treatment) consistent with such individual's written habilitation plan,
>
> "(ii) priority is given to transferring such individual to a family home, foster family home, or community living facility (including a facility certified in accordance with section 1905(d) that either meets the size and location requirements for a community living facility under section 1905(v)(1) or is treated as such a facility under section 1905(v)(2) . . . ."

The diversion of new admissions from facilities with 16 or more beds when coupled with the transferring of persons currently served in such facilities will result in a steady decline in the their enrollments. Each facility will eventually reach a point at which it cannot break even financially as its census declines. Although publicly operated facilities are able to turn to alternate sources of revenue to make up the deficit cause by declining census, private facilities rarely can make up prolonged deficits and will likely be forced to close. The closure of these facilities will result in the tragic and untimely "dumping" of large numbers of eligible individuals onto a service delivery system that is being revamped to provide new services to a broader range of individuals. Furthermore, it will seriously damage the individuals and entities that own and operate the facilities that are forced to close for financial reasons.

Recommendation #1:

The aggressive moves against large non-state operated facilities should be eliminated by grandfathering them into the broader service delivery system developed under the bill. The definition of "Community Living Facility" should be broadened to include ("grandfather") non-state operated ICFs/MR. Removing all non-state operated ICFs/MR from the freeze provisions might help protect the states against costly Boren Amendment litigation on behalf of private providers if the freeze of federal funds adversely affects reimbursement rates for private facilities.

II. Incentives to Downsize

Whether or not the definition of "Community Living Facility" is amended to include ("grandfather") existing non-state operated ICFs/MR, S. 1673 should be amended to include provisions to ensure a successful and smooth transition to the new service system. If the recommended changes in the definition of "Community Living Facility" are not adopted, the bill must include adequate protections for those adversely affected by the changes. The bill already includes protections for consumers and their families (Proposed amendments to Sec. 1921(d)(4)) and for employees of large public facilities (Proposed amendments to Sec. 1921(d)(6)(A)). It should also include protections for those who own/operate private facilities with 16 or more beds.

As noted above, there is a serious deficiency in the way the bill treats many existing private facilities. It establishes conditions which practically ensure their demise without adequately providing for the transition to the new type of service delivery system. There should be protections for the persons residing in larger private facilities and for the entities that own and/or operate them. Proposed amendments to Section 1921(d)(4) include the following provisions to protect persons who are residing in facilities that cease providing services:

> "(B) provide that alternate provisions are made for (and priority given to the development of) appropriate care (including basic maintenance if needed) and services for any individual with a severe disability eligible for medical assistance who has been living in a facility or institution which has been receiving payments for care, treatment, or maintenance of such individual under this title and which ceases to provide such care and services to such individual, other than at the request of the individual or such individual's representative; and
>
> "(C) set forth procedures for ensuring continuity of funding and the provision of services to an individual with a severe disability when an entity providing services to such individual for which payment is made under this title voluntarily discontinues operations or is terminated in accordance with paragraph (3)(G). . . ."

While recognizing the potential difficulties created in the transitional period, these provisions are inadequate to deal with the extent of the crisis that may occur when many private facilities are unable to continue operating.

Recommendation #2

Because the primary purpose of the S.B. 1673 is the expansion of community and family support services, the bill should be modified to include provisions for an incentive program that will encourage the **voluntary replacement** of services in existing large facilities (those with sixteen or more beds) with community and family support services for an equal or greater number of persons with severe disabilities.

Although such incentives are not normally covered by the Medicaid program, the dramatic policy reversal represented by the bill is a good justification for such a program. It should, however be a **one-time, time-limited program** that will allow those providers who have already committed resources to large facilities to make the transition to community and family support services without undue financial penalty.

Such an one-time, time-limited incentive program would probably best be part of the state implementation strategy. The bill should require states to include in their implementation strategy objectives for the voluntary reduction of the number of ICFs/MR having sixteen or more beds and permit them to reimburse providers for the costs incurred in **replacing** existing facility-based services with community and family support services for an equal or greater number of individuals with severe disabilities. If the internal revenue code could be simultaneously amended, the states could have the choice of reimbursing providers for the costs incurred and/or of granting tax credits equivalent to those costs not directly reimbursed. States could provide reimbursement and/or tax credits for up to ten years after the passage of the act and incentives would be available **only to providers replacing existing facility-based services for community and family support services**. It will be necessary to identify those costs involved in the replacement that will be directly reimbursable or eligible for tax credit.

Not only would such provisions protect current providers, but would provide an incentive for the development of home and community support services easing the transition to the new service delivery system.

III. "Clustered" Group Homes

If the recommended changes to the definition of "Community Living Facility" are not adopted, the bill may adversely affect group homes that are in close proximity to each other including many developed in Texas before 1982. Existing facilities with fifteen or fewer beds are divided into three groups in S.B. 1673:

1. Facilities treated as Community Living Facilities under Section 2(v)(2)(C)
2. Facilities meeting the same size and location requirements as Community Living Facilities but operating as ICFs/SNFs, etc.
3. Facilities with fifteen or fewer beds and that don't increase their number of beds but are not treated as Community Living Facilities (those that are "clustered" or in close proximity with one another or fail to meet other requirements of community living facilities).

The division is at times unclear and appears unnecessary. All three types are excluded from the freeze of federal funds to large facilities, but the third type is not be included as a full participant in the service delivery system. For example, the state implementation requires the admissions to the third type be restricted by the use of community and family support services:

> "(4)(A) in the case of individuals with a severe disability who are living in residential facilities which are not family homes, foster family homes, community living facilities, provide that—
>
> "(i) admissions to such residential facilities are restricted through the use of community and family support services . . . ."

There are many group homes in Texas that have more than eight beds and fewer than fifteen beds but are located next to or across the street from another group home of similar size. These facilities should not be adversely affected by this bill.

Recommendation #3

Change Section 2(v)(2)(C) as follows:

"(v) COMMUNITY LIVING FACILITY-

"(2) A facility that-
"(C) does not contain more than fifteen beds (exclusive of beds occupied by staff members), with no more than three such facilities in proximity to one another and which otherwise meets the requirements of paragraph (1);
shall be treated as a community living facility."

IV. Employee Protections

Provisions to protect the rights of public sector employees who are affected by the transfer of individuals to community or family living facilities should be extended to private sector employees as well.

Recommendation #4

While we grant that states cannot make the same guarantees of jobs, salaries and benefits to employees in the private sector, retraining and job recruitment should be provided by the state for private sector employees who lose jobs due to the transfer of those served to family or community living arrangements.

April 18, 1988

Members of the Senate Finance Committee
Subcommittee on Health
U.S. Senate
205 Dirksen Blvd.
Washington, DC 20510

Reference: Written testimony on S.1673/H.R. 3454

Dear Senator:

The Texas Health Care Association's membership includes facilities that provide care for private ICF-MR clients through community based programs. We appreciate the opportunity to provide written testimony to this Senate sub-committee to present views of our ICF-MR members regarding the Medicaid Home and Community Quality Services Act of 1987 (S.1673/H.R.3454).

Our Association opposes the above referenced bill as it is currently written. Some of our concerns regarding this bill are addressed below. Our major concern is the ability to monitor and ensure quality of care under this proposed system.

The proposed changes do not differentiate between large state institutions and the private ICF-MR community based program. It caps the federal Medicaid funds to all facilities over 16 beds. It also, directs the state to evaluate all clients in facilities with over 16 beds in an attempt to transfer patients to smaller facilities.

This bill is a budget buster. It greatly expands the basic services that the state must provide to persons with disabilities and makes Medicaid funds available to a new group of developmentally disabled individuals currently not eligible. It also expands the eligibility criteria for ICF-MR through age 50.

Expanded services are being proposed while Medicaid budget cuts are taking place. If Texas carried out the case management system proposed, the number of case managers in the program would quadruple. The number of surveyors to monitor the care is also estimated to quadruple. Draft figures from Texas Department of Human Services indicate that this would cost the state of Texas approximately $80 million the first year.

In 1974 Medicaid implemented the private ICF-MR community based program. At that time the private sector was asked to provide alternatives to "large public institutions." This bill changes that policy and indicates that the community based program is no longer an appropriate delivery system. We suggest that mentally

TEXAS HEALTH CARE ASSOCIATION
4214 Medical Parkway, P.O. Box 4554, Austin, Texas 78765 512-458-1257

retarded clients and their families should have a freedom of choice. This can be accomplished by maintaining a continuum of care for persons with developmental disabilities.

We are not aware of data that supports the model proposed in this bill as being more efficient or effective than programs currently in place. However, there are studies conducted in states who experienced huge deinstitutionalization efforts with clients placed in the community. These studies showed that the cost doubled and that the quality of care and health declined. There is not enough money in the state and federal budget to monitor the program proposed by this bill or to assure quality of care to those individuals.

Experience shows us that the more medically involved and profoundly retarded an individual is, the less appropriate and more costly a small facility is for them. The emphasis in the past has been to integrate mildly mentally retarded individuals back into the community. This bill, instead, isolates those individuals in small facilities that do not have programs in place to teach them techniques needed to survive in the community.

We recommend the following changes to S.1673/H.R.3454 prior to final passage:

(1) Include provisions to grandfather existing private ICF-MR facilities with over 5 beds; and

(2) If large private facilities are phased out, include financial incentives, such as tax credits, for these facilities to downsize to smaller 16 bed facilities over a specified period of time.

Again, we appreciate the opportunity to provide testimony and are available at anytime to provide further information on this testimony.

Sincerely,

Jerry Chapman

Jerry Chapman
Executive Director

JC:DC:slh

Texas Planning Council
for Developmental
Disabilities

118 East Riverside Drive, Austin, Texas 78704-9982
(512) 445-8867   TDD (512) 445-8004
Roger A. Webb, Executive Director

Lee Veenker, Chairman
Patricia J. McCallum, Vice-Chairman

April 18, 1988

Laura Wilcox, Hearing Administrator
United States Senate
Committee on Finance
Room SD-205 Dirksen Senate Office Building
Washington, DC 20510

Dear Ms. Wilcox:

The Texas Planning Council for Developmental Disabilities respectfully submits its testimony in support of S. 1673, the Medicaid Home and Community Quality Services Act of 1987.

We believe that Texans with developmental disabilities and their families could greatly benefit from the changes proposed in S. 1673. This legislation would remove the institutional bias from the Medicaid program and enable persons to exercise more freedom of choice in their lives to achieve greater independence, productivity and integration in their communities.

Sincerely,

Lee Veenker
Mrs. Lee Veenker
Council Chairman

Diana Luck
Diana Luck
Advocacy & Public Information
Committee Chairman

LV/mr

cc: Council members

Planning, advocating and monitoring services for thousands of persons with developmental disabilities throughout Texas.

An Equal Opportunity Employer

TESTIMONY
TO
SENATE COMMITTEE ON FINANCE
SUBCOMMITTEE ON HEALTH
ON
S. 1673, THE MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT OF 1987

The Texas Planning Council for Developmental Disabilities adds its voice to those of consumers, parents, advocates, professionals and others across the United States in support of the "Medicaid Home and Community Quality Services Act of 1987" (S. 1673).

Half of the 27 members of the Texas Planning Council are people who have developmental disabilities or their parents. All of the major state agencies that serve the more than 270,000 Texans who have developmental disabilities are also represented on the Council. Our Council voted unanimously to support S. 1673 in December, 1987.

This proposed legislation recognizes the needs and preferences of people who have developmental disabilities and would support them where they live -- at home and in the community.

Unlike previous Medicaid reform efforts, S. 1673 does not mandate the closing of large institutions. It does limit funding to the level of services being provided in the year of the bill's enactment, with a provision for inflation. (Since the Texas Department of Mental Health and Mental Retardation Strategic Plan calls for continued community placement of 300 persons per year, this limit on level of funding would not jeopardize services in large institutions in our state.)

Nonetheless, the current system for Medicaid has an institutional bias that S. 1673 would remove. As a nation we are moving away from institutional placements for people who have severe disabilities. And yet we have not developed the support systems to allow them to live in the community independently and productively.

Families who take care of family members with severe disabilities in their own homes have little or no support or respite from the demands placed on their time and energy. Young adults with severe disabilities leave the public schools with no plan for the future and no constructive way to spend their time. Adults with severe disabilities often have no work and no opportunities for social interaction and become financially dependent and socially isolated.

These individuals and families face an all-or-nothing dilemma under the current Medicaid law: they can choose segregated institutional placements or they can choose community life, with none of the supports available that foster independence or productivity. (Attached to our testimony is a profile, written by Jennifer Cernoch, project director for the Texas Respite Resource Network, a model project that the Texas Planning Council supports. The story she tells is tragically an all too typical illustration of the effects of our current system.)

S. 1673 offers a genuine alternative. Under this bill, individuals and families would no longer have to opt for a greater level of care than they want or need. Instead they would be eligible for the appropriate support at home or in the community that can make independent living a lifelong reality for people with severe disabilities.

S. 1673 is a practical step for the Congress to take toward meeting the needs of people who have developmental disabilities. It is also the right step for the Congress to take. It is a step toward a future where people with developmental disabilities will have the support to live independent, productive lives within their own communities, and where society will reap the benefits of their talents and contributions.

We urge Senate passage of S. 1673 because we must recognize that persons with developmental disabilities not only have the capability to make positive contributions to society but a right to the opportunity.

Thank you for your consideration in this matter.

The Story of Melissa

Texas Respite Resource Network (TRRN) receives numerous calls each month from families throughout Texas seeking respite care services. It is difficult most of the time to find these services without a coordinated service delivery system and without a central agency to monitor the few services that do exist. The following story is about a little girl and her family, not very different from many families in Texas.

Melissa is a 5 year old girl with honey blonde hair and big blue eyes. I had the wonderful opportunity to meet Melissa and her mother while Melissa was hospitalized for gastrostomy surgery. As I walked into the hospital room, I found the mother very distraught and almost in tears. She had just found out that Melissa was so dehydrated that a gastro tube would have to be inserted in order for her to live.

As I talked to the mother to gather more information about her needs and the needs of Melissa, I found that I was at a loss to help her. Melissa and her mother live about 150 miles from San Antonio in South Texas and would not be able to readily use The Respite Station (our model pilot respite care project) for the relief that they both desperately need. I knew from our statewide networking that no respite services were available in Melissa's home town. As I listened to the mother, I knew that if support services were not available to her, that Melissa would probably be left in the care of someone else.

Melissa's mother shared with me her experiences of having a child with special needs. One month after her birth, Melissa began seizuring resulting in severe brain damage. Since that time, Melissa has been on medications to control the seizures and is currently functioning at around a 6 to 8 month old level. Melissa's biological father left home shortly after her birth because of the emotional stress and strain of caring for a child with special needs. The mother stated that their divorce was a direct result of Melissa's special needs. For five years, Melissa's care has been the sole responsibility of her mother.

When the mother lived in North Texas with Melissa, she was able to receive weekend respite through a TDMHMR state center. This occasional relief helped the mother with the constant care that was required by Melissa. Since the family moved, respite services have not been available. As the mother has stated, she has tried to "fight" the system for her child but has been unsuccessful. Melissa's mother has remarried however, due to difficulties in the home, the family does not have any support services to help maintain their family unit.

I informed the mother that TRRN had been discussing offering overnight weekend care at The Respite Station but that this would probably not occur until the summer months. TRRN through Baby-Helpline at Project ABC was able to secure some medical supplies, formula, and special diapers for Melissa. The biggest service that we could not provide was RESPITE CARE and long-term support services to this family. Melissa's mother has been trying for months to obtain a state school placement for Melissa, but was unsuccessful. After meeting on a number of occasions with representatives from her community MHMR, Melissa's mother was informed that state school placement would likely take a few years. Melissa's mother sought help from the Texas Department of Human Services but was informed that respite services were not available. The family was informed that if Melissa was placed outside of the home, she would qualify for care and that that care would be provided through her Medicaid. No in-home care was available to Melissa and her family to keep the family intact. I asked the mother point blank that if she had respite care services and long-term support services if she would keep Melissa at home. She responded, "Probably YES, I love her and she belongs to me but I can't continue like this."

Less than one week after Melissa was discharged from the hospital, the mother without very many options, placed her in a nursing care center at a cost to our state of approximately $20,000.00 (reimbursement rate plus SSI benefits). I spoke with the mother the day after she placed Melissa in the center. She was very upset about leaving her child but what few options did she have? Our system has failed this little girl and her family. In a way, I have failed this little girl also. I had nothing to offer to help this family maintain stability, togetherness, and unity.

I know that this story is not any different from the thousands of families that currently live in Texas. This story may not even be as tragic as many that I have heard. What makes it different is that I know in my heart that this family might still be together if only we had the services.

In a follow-up conversation that I had with the mother to obtain her permission to use the story of Melissa for public awareness purposes and to hopefully change our statewide system, I was informed that the family has had the opportunity to visit Melissa on a couple of occasions. These visits are few and far between because of the traveling time that is involved. Since Melissa's admission into the nursing care center, she has been hospitalized once for complications resulting from her surgery. The family is considering moving in order to find employment which will make them even further from their daughter. As I informed the mother of the cost of Melissa's care in the nursing care center, the mother informed me that she would be able to care for her daughter at home at less than half the cost of the nursing care center if only these funds and services were available to her. In so many instances, without respite care and long-term support services, families must choose the option of placing the care of their child in an out-of-home setting. TRRN works with many families throughout Texas and in at least five instances, families have chosen to place their son or daughter in out-of-home settings because the lack of a coordinated service delivery system in respite care.

By: Jennifer M. Cernoch, Ph.D.
Director
Texas Respite Resource Network
Santa Rosa Medical Center
519 W. Houston
San Antonio, TX 78285

March 25, 1988

Laura Wilcox
Hearing Administrator
U.S. Senate
Committee on Finance
205 Dirksen Senate Office Building
Washington DC 20510

Dear Ms. Wilcox:

I am writing to voice my strong support for SB.1673, the Medicaid Home and Community Quality Services Act. I was pleased to hear that the Sub-committee of Health held a public hearing on this issue on March 22, 1988. This bill is essential legislation to assure people with disabilities the opportunity, right and choice to live in the community. At present, our county, which is Milwaukee county, demonstrates a significant bias toward institutionalization. 87% of Medicaid funding is utilized to provide services to people in facilities of 16 beds or larger. This means that only 13 % of these public dollars are available for individuals with developmental disabilities to live in the same manner, quality and respect that the able bodied population demands and takes for granted.

I am fortunate to have experience in working with individuals with developmental disabilities in both nursing home and community residential settings. It is without question that I can attest to the quality of life which is achieved in community living. From both a fiscal and humanitarian context we have demonstrated poor public policy in our country.

The Medicaid national average institutional per diem has risen to $127.00, even though the census of institutions has continued to decline year after year as more people strive to maintain themselves in community settings. It is clear that the focus of services for people with developmental disabilities has shifted, and rightly so, toward a community based model that emphasizes personal dignity and freedom of choice. The Medicaid Home and Community Quality Services Act is essential if we as a nation truly want to live up to our standard of liberty and justice for all.

Sincerely,

Barb Tylenda

Barbara Tylenda
7568 Drake Lane
Franklin WI 53132
414/425-4068

STATEMENT FOR THE RECORD

SB 1673 Medicaid and Community Quality Services Act 1987

I, Robert R. Thomas, want to make a statement for the record, that I oppose SB 1673. I specifically oppose that section of the proposed bill that freezes funds to any facility that has 16 or more disabled individuals in their care. The bill assumes that 100% of the mentally retarded should be in single family dwellings or apartments, and that all facilities larger than 16 are necessarily bad. Those assumtions are not only erroneous, but completely unrealistic. My son is 30 years old and currently works in a sheltered workshop and is very active in Special Olympic programs. We live in a rural area where there is no mass transit and the "community group homes" are really mini-institutions that isolate the retarded with very limited recreational opportunities. I firmly believe that the mentally retarded should have the freedom of choice to an alternative other than small single homes or apartments which this proposed bill has mandated for them. What happened to individual rights.

My whole family has been very active in programs for the mentally retarded on both a volunteer and professional level. I was President of the PTA at John S. Charleton School when my son was under the age of 20 and received training under the Department of Public Instruction. I joined the Board of Directors of a sheltered workshop about 5 years before my son would leave the school system, so I could make a contribution to making it as successful as possible by the time my son was eligible to attend. I have been President of the Board of Directors five out of the last fifteen years I have been on the Board. When I first joined the Board; the workshop had about 3,000 square feet of space, had an annual budget of about $150,000.00, and served about 20 clients a day. The workshop now has 70,000 square feet of space, seves 370 people a day, and has an annual budget of over 3 million dollars. I have also been a member of the Delaware Association for Retarded Citizens for about 20 years and have served on the vocational rehabilitation committee for several years. My wife was instrumental in establishing a recreational bowling program for the retarded over 20 years ago that is still active in the community today. She was also awarded the Delaware Association for Retarded Citizens Recreation Award of the Year in 1982 for her work in arranging trips to ballgames, circuses, ice shows, and social events in the local area. She organized the first area Special Olympic Bowling Meet (1985). My daughter worked as a volunteer for many years for dances, aerobic training, and Special Olympics. She also worked as a counselor in an independant living program that placed mentally retarded adults in local community apartments. My son-in-law, with his degree in Psychology, is an Assistant Director in a sheltered workshop and has volunteered as a Special Olympic team coach for many years. What I am trying to say, is that my entire family has been totally involved in programs for the mentally retarded at all levels and I feel we are more than qualified to speak on the issues affecting the retarded.

I believe in quality residential housing for the mentally retarded that is service oriented and that provides the freedom of choice to the individual, and not mandated, is the best solution. The proposed bill allows for up to three clustered homes in one area, but should be amended to allow 8 to 10 clustered homes in rural areas. This would allow the Administrator or Director to provide recreational and social programs on the site without the necessity of busing. It would allow for paved streets and sidewalks for every individual to walk to the community center or access by wheelchair clients without the need for special vans. Our workshop spent over a quarter of a million dollars last year in an attempt to provide additional transportation for recreational services. The cost to pay salaries for highly qualified professionals with a masters degree or doctorate to administer quality programs, can not be supported by small single homes scattered all over the area. It is not economically feasible to purchase 10 separate acre lots when you could purchase a single parcel of land at a much lower cost per acre. It is obvious discrimination to mandate that when 16 or more mentally retarded adults want to live in a rural community with a special quality of life, they could lose their benefits. We have a senior citizen complex in our community that has over 100 people living in the same building because of common interests and the need for services. Many of these senior citizens have their rent subsidized by federal funds and no one has tried to tell them they can not live in groups of 16 or more. Lets treat the mentally retarded with at least the same respect that we show our senior citizens and give them a freedom of choice.

I, and my whole family, oppose SB 1673 and any other bill that would freeze funding to any facility, existing or planned, that would provide quality residential care for the retarded. I believe in quality residential housing for the retarded, with the freedom of choice to live in the type of housing arrangement that they feel comfortable in. Please do not mandate that they must be isolated to "mini-institutions" with limited services, but give them at least the same considerations we give our senior citizens to live with their own social group if they so desire. Lets use the limited dollars available to provide vitally needed services to the retarded and not waste our money on high paid professionals spending much of their time riding around in automobiles between isolated group homes and getting paid .22 cents/mile to boot. Lets spend our money on people and not on transportation.

Sincerely

Beatrice M. Thomas

Robert R. Thomas　Beatrice M. Thomas

69 Oakcrest Drive
Dover, De. 19901

United Cerebral Palsy Of Southeastern Wisconsin, Inc.
230 West Wells Street, Suite 502, Milwaukee, Wisconsin 53203

Telephone: (414) 272-4500

March 25, 1988

Laura Wilcox
Hearing Administrator
United States Senate
Committee on Finance
205 Dirksen Senate Office Building
Washington DC 20510

Dear Ms. Wilcox:

On behalf of the 5000 people with cerebral palsy and other disabilities and their families that we come into contact with through our statewide services, I am writing to voice our strong support for Senate bill 1673, The Medicaid Home and Community Quality Services Act of 1987.

Our agency strives to provide high quality community based services that help families with a disabled child to remain intact, that support adults with cerebral palsy living in their own apartments, and that assist parents of school age children to maximize their child's potential in the public school system.

A main focus of our effort has been to avoid unnecessary institutionalization of children and adults with cerebral palsy, and to provide a safe transition back to the community for those living in State Developmental Disability Centers and nursing homes. We have been fortunate to take part in the process whereby people, even those with the most severe disabilities, are supported in their attempts to live lives of personal dignity and freedom. However our current service delivery system is grossly under funded, and we are unable to meet the needs of all who desperately need community support. Because of this, we have 3000 people with developmental disabilities, many of whom have cerebral palsy, living in nursing homes across the state. Our own Milwaukee county is faced with the problem of trying to relocate almost 400 people who are inappropriately placed in area nursing homes. We also still have 1900 people living in our State Centers. Much of this problem could be eliminated by removing the institutional bias from current Medicaid law and entitling people with disabilities and their families to the services they need, services that S.1673 mandates such as attendant and respite care, family support, supported employment, and case management. Without these provisions, the "world of the waiting list" will continue, and people with disabilities will be denied the basic choices we all take for granted, choices of where to live, who to live with, where to work and play, and who to have for friends. This legislation will be better for all Americans, for it is certainly true that no people are free until all people are free.

Sincerely,

Joyce Altman

Joyce Altman
Executive Director

2025 Gemini Dr.
Bastrop, LA 71220
March 14, 1988

Ms. Laura Wilcox, Hearing Administrator
United States Senate Committee on Finance
Room SD-205
Dirksen Senate Office Building
Washington, D.C. 20510

Dear Ms. Wilcox:

As a parent of a daughter residing at Holy Angels Residential Facility in Shreveport, Louisiana, I am deeply and personally concerned about S.1673, the Medicaid Home and Community Services Act of 1987, as it is written now. The Chaffee bill hearing will be held March 22 at 9:30 a.m.

Holy Angels Residential Facility is located in Shreveport, LA., ID #72-0628035 with 179 residents (bed capacity of 184). The cost per client is far less than any other per diem in the state, especially the community homes. Financially there are many, many other factors to consider before passing this bill as it is written.

Please give serious consideration to amend this bill to insure quality care for those residing in ICF/MRs at this time. They must receive the same level of funding as those in community residences. We do support reduction in the size and population of larger "institutions" but not at the risk of financial withdrawals that would jeopardize the total care of these clients now being served (freezing funds).

Thank you for every consideration in this matter.

Sincerely,

Barbara A Welch

Mrs. Charlie C. Welch

Sam M. & Mary S. Wailes
Rt. 5 Box 129-A
Coushatta, La. 71019
March 10, 1988

Ms. Laura Wilcox, Hearing Administrator
United States Senate Committee on Finance
Room SD - 205
Dirksen Senate Office Building
Washington, D.C. 20510

Dear Ms Wilcox:

Re: S-1673 Medicaid Home & Community Quality Services Act of 1987

Our profoundly retarded daughter Rita Sue Wailes, age 25, has been a resident of Holy Angels Residential Facility for the past 10 years. She has received a total array of services found only in ICF/Mrs needed to meet her requirements.

The present Bill S-1673 discriminates against the profoundly and severely retarded in that it restricts funding for those in dire need. We urge you to reconsider S-1673, ammend the bill to protect those citizens in ICF/Mrs by allowing the same level of funding as those in Community residences.

Please consider our urgent request.

Sincerely,

Sam M & Mary S. Wailes

Sam M. & Mary S. Wailes

Public Hearing of the U. S. Senate Finance Committee
Concerning Senate Bill 1673
The Medicaid Home and Community Quality Services Act of 1987

Testimony of The Wisconsin Parents Coalition, Inc.
P.O. Box 17954
Milwaukee, Wisconsin, 53217

Presented by
Philip W. Harper
Vice President

I am Philip W. Harper residing at 11907 Timberline Lane, Hales Corners, Wisconsin 53130. I am representing W.P.C., The Wisconsin Parents' Coalition for the Retarded, Inc.

As Vice President of W.P.C., I am directed to oppose S. B. 1673 in the following areas.

A. FREEZING OF FEDERAL FUNDS FOR LARGE INSTITUTIONS.

In the bill there is a cap placed on the funding of large institutions by limiting the increase in funding to only those amounts above a 6 % rate of inflation. In a period of 5 years there could be a funding loss of up to 30 % as written in S. B. 1673. This would result in a lower quality of service. The population of large institutions today require greater services. A continuation of the present system of funding is needed as a minimum to meet the Federal standards required to prevent decertification.

B. STANDARDS OF SERVICE - LARGE INSTITUTIONS VERSUS COMMUNITY FACILITIES.

In S. B. 1673 there is a provision that large facilities would continue to be measured by Federal standards and inspection procedures. As stated in this bill, the States would establish and monitor all community facilities. With this procedure we could have 50 sets of standards for Federally funded facilities. This could result in a reduced quality of standards in some areas. Standards should continue to be established for community facilities by the Federal government with a quality and quantitative "look behind" inspection system.

C. MANDATORY TRANSFERS AND FREEDOM OF CHOICE

This bill in its present form should be revised to provide adequate protection for parents and guardians as to their rights to determine the services administered to their ward. The powers of guardians and parents are severely restricted in S. B. 1673 in this regard. Who better than a concerned parent or guardian to determine the welfare of that handicapped person?

As stated at the beginning of my presentation, W.P.C. is in opposition to S. B. 1673. The three major areas as listed demand a cancellation of this bill and a revised bill to be issued correcting these deficiencies.

WRITTEN STATEMENT TO
SENATE COMMITTEE ON FINANCE
REGARDING S.1673

The Wisconsin Department of Health and Social Services is the administering agency in Wisconsin for the Medicaid program, for institutional services for people with developmental disabilities, and for community services for people with developmental disabilities. The Department strongly endorses the enactment of S.1673, with two amendments which we will discuss later in this written testimony.

There are currently 6,500 people with developmental disabilities living in Wisconsin institutions, primarily because of the availability of Medicaid funding for such institutional services. The Medicaid Home and Community Quality Services Act would eliminate the current institutional bias of the Medicaid program, give the choice of living in the community to people now in institutions, and provide a stable source of funding for other individuals in need of support to remain in their homes and communities.

We believe this bill is a significant improvement upon the Community and Family Living Amendments introduced during the 99th Congress, which we could not support. The previous proposal would have mandated a pace of deinstitutionalization which Wisconsin would not have been able to meet. S.1673 would allow us to continue our very careful, highly individualized approach to assuring that people with developmental disabilities in Wisconsin institutions return to their homes and communities with the full support and services they need. Equally important, it will provide the funding needed to allow us to serve children, families, and adults in need of services in our communities who may otherwise be forced to consider institutional placements.

We cannot, however, fully support the enactment of S.1673, without an amendment to limit the maximum age of onset of disability to 22. This amendment would better correspond to the target group of people with developmental disabilities typically used by federal and state government. The provision in the currently proposed legislation which incrementally raises the maximum age of onset up to age 50 introduces both programmatic and fiscal uncertainties which are difficult, if not impossible, to assess at this time. This provision would appear to us to jeopardize the fiscal neutrality of the legislation for both federal and state purposes. We thus strongly recommend that the very important issues of financing services to people who become severely disabled during adulthood be considered through other legislation.

A less significant, yet important concern relates to the prohibition against lodging case management services with a provider of direct services. While we strongly agree with the concept of the separation between the delivery of "direct services" and the responsibility for case management for those services, we are concerned that this provision would prohibit us from using our county agencies as the focal point for the coordination of all residential, vocational and support services for people with developmental disabilities. While the majority of services are delivered through contracts between providers and our county departments of community services, counties could be construed under S.1673 to be providers of services. This would prohibit us from utilizing our current highly effective case management system. We thus recommend an amendment which would exempt publicly administered case management systems from the prohibition against this responsibility resting with a direct services provider.

With the inclusion of the two amendments described above, Wisconsin would enthusiastically support S.1673. It is the best vehicle we have yet seen for the type of Medicaid reform which is desperately needed if states are going to be able to end more than a century of segregation of people with severe disabilities, and provide the supports that people with developmental disabilities need to live in real homes, to work at real jobs, and to become friends and neighbors with people who do not have obvious disabilities.

MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT OF 1987 (S. 1673/H.R. 3454)

MY NAME IS NANCY WARD AND I AM THE MOTHER OF DIANNE WARD, SHE IS 26 YEARS OLD AND IS A RESIDENT OF FORT WORTH STATE SCHOOL, FT. WORTH, TEXAS. DIANNE HAS BEEN A RESIDENT OF STATE SCHOOLS FOR 16 YEARS, SHE WAS IN CORPUS CHRISTI STATE SCHOOL FOR 6 YEARS AND 10 YEARS IN FT. WORTH STATE SCHOOL. DIANNE IS PROFOUNDLY RETARDED, SHE FUNCTIONS AT A 16 MONTH LEVEL, HAS NO SPEECH, CEREBRAL PALSY, AMBULATION PROBLEMS, VISUAL DISORDER, BEHAVIOR PROBLEMS, MANY SEVERE MEDICAL PROBLEMS AND OTHER PHYSICAL DEFECTS. DURING MY PREGNANCY I WAS GIVEN PROVERA TO PREVENT A POSSIBLE MISCARRIAGE AFTER SURGERY FOR AN OVERIAN CYST. DIANNE IS THE YOUNGEST OF THREE DAUGHTERS. MY OLDEST IS AN ATTORNEY AND THE MIDDLE DAUGHTER IS AN ACCOUNTANT, THEY BOTH HAVE EXCELLED IN SCHOOL AND NOW IN THEIR CAREERS.

WHEN DIANNE WAS AGE 2, WE LIVED IN MIDLAND, TEXAS AND WE ENROLLED HER IN THE OPPORTUNITY CENTER AND CEREBRAL PALSY CENTER FOR SPECIAL TRAINING THAT INCLUDED SPEECH AND PHYSICAL THERAPY, SHE REMAINED THERE FOR 4 YEARS, WE THEN MOVED TO CORPUS CHRISTI, TEXAS. DIANNE WAS THEN ENROLLED IN THE OPPORTUNITY CENTER AND HAD PRIVATE SPEECH AND PHYSICAL THERAPY UNTIL SHE WAS 10 YEARS OLD. WITH ALL THE TRAINING DIANNE HAS HAD, SHE IS STILL UNABLE TO TALK OR WALK NORMALLY. SHE DID MAKE SOME PROGRESS, SHE CAN FEED HERSELF, BUT SHE IS STILL NOT TOILET TRAINED AND HAS NO SENSE OF SELF PROTECTION, SHE IS STILL LIKE A 16 MONTH OLD BABY EXCEPT SHE IS NOW 5 FT, 8 Ins. TALL AND WEIGHS 172 lbs. AND VERY STRONG. AT AGE 10, WE REALIZED DIANNE NEEDED SPECIAL TRAINING AND VERY PROTECTIVE CARE THAT WAS IMPOSSIBLE TO GIVE AT HOME SINCE SHE DID NOT REALIZE OR HAVE ANY FEAR OF DANGER, MORE THAN ONCE SHE WANDERED OUT OF THE HOUSE AND INTO THE STREET POSING A DANGEROUS SITUATION FOR HER, A HOT KITCHEN STOVE MEANT SHE COULD TOUCH TO TEST IT, SHE ALSO PUT INEDIBLES IN HER MOUTH AND SWALLOW THEM. SHE HAD TO BE WATCHED EVERY MINUTE, EVEN DOING THAT, SHE STILL HAD ACCIDENTS AND WAS INJURED. WE THEN DECIDED TO ENROLL HER IN THE CORPUS CHRISTI STATE SCHOOL SO SHE COULD HAVE SOME FREEDOM WITH SPACE TO WALE WITHOUT CONSTANT SUPERVISION, SHE REMAINED THERE UNTIL OUR TRANSFER TO FT. WORTH AND WAS THEN TRANSFERRED TO FT. WORTH STATE SCHOOL. DIANNE IS VERY HAPPY AND WELL TAKEN CARE OF, SHE CONTINUES TO MAKE PROGRESS WHICH I AM PROUD OF, BUT SHE STILL FUNCTIONS LOW EVEN THOUGH SHE HAS HAD MANY OPPORTUNITIES THROUGH INTENSIVE SPEECH AND PHYSICAL TRAINING AND CONSTANT ATTENTION AND LOVE FROM HER ENTIRE FAMILY.

I AM VERY CONCERNED ABOUT S. 1673/H.R. 3454) IF PASSED, THE LARGE INSTITUTIONS NEEDED BY MANY CITIZENS WILL BE CLOSED AND WILL LEAVE MANY PEOPLE LIKE MY DAUGHTER WITHOUT THE CARE AND PROTECTION SHE NEEDS JUST TO SURVIVE. THE LARGE FACILITY IS THE LEAST RESTRICTIVE ENVIRONMENT FOR MANY SEVERE AND PROFOUND PEOPLE WITH MENTAL RETARDATION.

THE CIVIL LIBERTARIANS AND DEVELOPMENT DISABILITY INDUSTRIALISTS WHO ARE SUPPORTERS OF THESE BILLS ARE BIASED AGAINST LARGE INSTITUTIONS AND HAVE PRESENTED MISLEADING OUTCOMES FOR MANY WHO HAVE GONE TO LIVE IN THE COMMUNITY AND THEY FAIL TO REPORT THE TRAGEDIES THAT HAVE OCCURRED IN SOME SMALL GROUP HOMES, THEY ONLY REPORT NEGATIVE INFORMATION ABOUT LARGE FACILITIES. MANY PRIVATE PROVIDERS SUPPORT THIS BILL BECAUSE THEY CAN SEE AN OPPORTUNITY TO INCREASE THEIR INCOME. BUT THE PRIVATE PROVIDERS WILL NOT TAKE PEOPLE LIKE MY DAUGHTER BECAUSE IT WOULD BE IMPOSSIBLE TO CARE FOR HER AND MAKE A LARGE PROFIT BECAUSE OF THE SPECIAL CARE SHE NEEDS. SOME ADVOCATES AND ADVOCATE GROUPS WHO CLAIM TO REPRESENT ALL RETARDED PEOPLE DO NOT REPRESENT PEOPLE LIVING IN LARGE INSTITUTIONS WITH SEVERE AND PROFOUND RETARDATION. THESE SAME ADVOCATES AND GROUPS ARE IN THE COMMUNITY GROUP HOME BUSINESS, SO IT IS OBVIOUS THEY ARE ONLY INTERESTED IN THE PROFIT THEY CAN MAKE, THEY SHOW NO INTEREST OR CARE FOR THE MANY RETARDED PEOPLE WHO WILL BE DUMPED OUT OF THE LARGE INSTITUTIONS WHO WILL BECOME THE HOMELESS STREET PEOPLE, THE STREET PEOPLE POPULATION HAS INCREASED TREMENDOUSLY SINCE THE DEINSTITUTIONALIZATION MOVEMENT. IT IS SAD TO SEE SO MANY STREET PEOPLE WITH MENTAL ILLNESS AND RETARDATION SUFFERING FROM LACK OF MEDICAL CARE, FOOD, SHELTER AND PROTECTION, I WONDER WHAT KIND OF A SOCIETY WE HAVE BECOME. I WORRY ABOUT MY DAUGHTER BECOMING A HOMELESS STREET PERSON IF I AM UNABLE TO CARE FOR HER, AND IF I SHOULD DIE OR BECOME ILL THIS IS POSSIBLE.

THE MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT OF 1987 (S. 1673/H.R. 3454) DISCRIMINATES AGAINST ALL PERSONS NEEDING AND BENEFITING FROM THE PROTECTION AND CARE THAT CAN ONLY BE GIVEN BY A LARGE FACILITY WITH ALL THE SUPPORT SERVICES LOCATED ON THE CAMPUS. MEDICAL AND DENTAL CARE IS VERY DIFFICULT TO OBTAIN IN THE COMMUNITY BECAUSE MENTALLY RETARDED PEOPLE ARE NOT ALWAYS COOPERATIVE AND REQUIRE MORE TIME TO TREAT. PEOPLE WITH MENTAL RETARDATION ARE THE MOST HELPLESS, HOPELESS AND VULNERABLE MEMBERS OF OUR SOCIETY AND THE PASSAGE OF THIS BILL WILL BE UNFAIR TO THEM AND WILL HURT THEM GREATLY. THE LARGE INSTITUTION IS THE ONLY PROVEN, EFFECTIVE, EFFICIENT AND PROTECTIVE METHOD OF CARING FOR THE SEVERE AND PROFOUND MENTALLY RETARDED. THIS BILL ALSO DISCRIMINATES AGAINST THE FAMILY WHO WILL BE FORCED TO CARE FOR THEIR CHILD, IT WILL BE NESESSARY IN MANY CASES FOR BOTH PARENTS TO QUIT WORK TO CARE FOR THIS CHILD WITH SPECIAL NEEDS. THEY WILL NO LONGER BE TAX PAYING CITIZENS AND IT WILL BE NECESSARY TO GO ON WELFARE.

AS A TAX PAYING CITIZEN AND VOTER I WISH TO EXPRESS MY OPPOSITION TO THE MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT OF 1987 (S. 1673/H.R. 3454), I HOPE BEFORE ANY ELECTED OFFICIAL VOTES FOR THIS DISASTROUSLY BILL THAT WILL HURT SO MANY CITIZENS, THEY WILL MAKE AN EFFORT TO LEARN THE TRUE FACTS, NOT JUST LISTEN TO PEOPLE WHO STAND TO MAKE A PROFIT. MY DAUGHTER WILL NEED THE LARGE FACILITY FOR AS LONG AS SHE LIVES AND IT WILL BE NEEDED BY MANY CHILDREN IN THE FUTURE.

NANCY WARD
4636 HARLEY AVE.
FT. WORTH, TX. 76107
817-735 9691

Mark & Catherine Wuchter
5509 West 85th Street
Burbank, Illinois 60459

I am writing to ask you for your support in passing S1673 "The Medicaid Home & Community Quality Services Act of 1987" and its companion bill H.R.3454.

Disabled persons have rights too. How wonderful it would be if we would wipe out birth defects and disabilities caused by serious illness and injury. Unfortunately, we cannot do this so it is important that we protect disabled persons and give them a chance for decent lives. The future is so uncertain and there are no guarantees. Most people do not concern themselves with these ideas because they lead normal lives. However, everyday there are babies being born with birth defects and children and adults left totally disabled as a result of serious illness or injury. It can happen to anyone.

Our six year old daughter, Heather has cerebral palsy and is totally dependent. We are aware that the services to disabled persons in Illinois has suffered drastically in the last ten years. This frightens us and we are afraid to think about the future. We have been on a waiting list for nearly two years for some services. What will happen to Heather when we are too old to care for her? What if something should happen to us now? Where would Heather go and what kind of care would she receive? She would not be able to take care of herself. We want her at home as long as we are physically capable of caring for her. She has a wonderful family life, and inspite of her disabilities, she is a very happy little girl. We want her to be happy in her adult life also, and passage of this bill could mean just that.

We would like to guarantee a promising future for Heather, but we realize we cannot do it alone. Won't you please help Heather and all others with disabilities by supporting S1673 "The Medicaid Home and Community Quality Services Act of 1987" and its companion bill HR3454?

Sincerely,

Mark & Catherine Wuchter

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